# UNDERSTANDING THE INTERSECTION OF LONELINESS AND RECOVERY SETTING IN OLDER CARDIAC PATIENTS

By

**Catherine A. Macomber** 

# A DISSERTATION

Submitted to Michigan State University in partial fulfillment of the requirements for the degree of

**Social Work – Doctor Philosophy** 

#### ABSTRACT

# UNDERSTANDING THE INTERSECTION OF LONELINESS AND RECOVERY SETTING IN OLDER CARDIAC PATIENTS

By

## **Catherine A. Macomber**

Loneliness has significant negative impact on health. Loneliness is the difference between the amount of social support you expect to receive and the amount you perceive you are getting. Age is one risk factor of loneliness, and life events such as a move to a nursing home or the need for professional care to provide assistance with Activities of Daily Living also increase the risk of loneliness. There is little evidence comparing the experience of loneliness between settings of nursing homes and at home with home care, and yet much current policy sees agingin-place, staying in your own home, as the most appropriate setting for growing older. This mixed methods study compares the experience of loneliness in two settings, nursing home and at home, and the influence demographics and social support have on this relationship. The theoretical framework used is the Health Belief Model.

Data for the quantitative secondary data analysis came from the Health and Retirement Study. The qualitative interviews were conducted in the Great Lakes Bay Region with older adults who were recently discharged from the hospital to home or nursing home settings. Interpretative Phenomenological Analysis was used to understand the meaning interviewees made of their experience of discharge from the hospital, their expectations and perceptions of social support, and their feelings (or lack) of loneliness.

The study findings were mixed when comparing loneliness outcomes between nursing home and at home settings with quantitative data indicating no difference and qualitative data indicating some differences. Age, marital status, ethnicity, and perceived socioeconomic status were all significant predictors of loneliness. Social support from spouse, children, other family, and friends was found to have an influence on the experience of loneliness. Social support from children was found to be a moderator of loneliness between settings, with decreased loneliness associated with the presence of positive social support from children. These results were confirmed with qualitative interviews which helped to clarify why these differences in loneliness occur.

Interventions to address loneliness depend on an understanding of the underlying causes of the discrepancy between expected and perceived support and yet are often only focused on adding more people to the life of an individual who says they are feeling lonely. This does not address either expectation or perception. Using the Health Belief Model to interpret these findings, this study suggests that health care providers need to know what older adults expect when they contemplate social support and what they perceive when they are recovering. Findings from this research may lead to additional intervention strategies for prevention of and intervention with individuals who are experiencing loneliness. Social work practice, education, research, and policy may all be influenced by the findings of this study. The findings provide an understanding of why loneliness differs between settings and what social support may do to reduce the loneliness individuals experience. Copyright by CATHERINE A. MACOMBER 2017 To my Family.

#### ACKNOWLEDGEMENTS

I am most grateful for the mentorship and guidance of my chair, Amanda Woodward. She has been an invaluable resource and I appreciate all of her time and attention.

My committee members have provided excellent feedback and encouragement throughout this process. I have been fortunate to have such a wealth of knowledge throughout my doctoral education.

Upon admission to the PhD program at MSU, I became part of an excellent cohort of peers. I would not have been successful without their on-going support. Commuting to campus did not encourage a great deal of social interaction, and yet this wonderful group of people included me in their lives through social media and Zoom. I appreciate them. Thank you.

This has been a long journey. I was encouraged to start a PhD program by Dr. Lucy Mercier and Dr. Donald Bachand while still pursuing my Master's degree. When I saw them in the hallway on SVSU's campus, I would hear "have you applied for your PhD yet?' Their encouragement and support have been invaluable.

There are many others to whom I owe much and please know that I understand that without your support I would not have made it this far.

Being a wife, mother, daughter, sister, granddaughter, aunt, friend, niece, cousin, and colleague AND a PhD student is challenging for everyone. I am successful only because my family, friends, and colleagues supported and encouraged me every step of the way.

Thank you Dad and Grandpapa. Tight shoes have helped.

Thank you Aunts. I have on a little lipstick.

vi

Thank you Matt. Thank you Emily and Grace. Thank you Mom. There was never a part of this journey that you were not there to hold my hand and tell me that I would get through it. I absolutely could not have done it without you. I love you, I am grateful to you, and I am looking forward to reclaiming my roles in your lives.

And so, with that, I have only two other things to say.

Call me Doctor and What's next?

# TABLE OF CONTENTS

LIST OF TABLES	xi
LIST OF FIGURES	xii
CHAPTER 1	1
INTRODUCTION	1
Statement of the Problem	1
Theoretical Framework	2
Significance of the Study	4
Overarching Goal of the Study	6
Organization of the Dissertation	7
CHAPTER 2	
LITERATURE REVIEW	8
Theory	8
Health Belief Model	8
Loneliness	12
Previous loneliness research	
Measurement of loneliness	
Social Support	
Life Transitions	
Recovery setting	
Sociodemographics	25
Loneliness, Social Support, Life Transitions, and the Health Belief Model	
Study Methods	
Importance of this Study	
Loneliness as a health outcome	
Gaps in existing literature	
CHAPTER 3	
METHODOLOGY	
Quantitative Data	34
Data Source – The Health and Retirement Study	34
Sample	
Dependent Variable	
Loneliness	
Independent Variables	36
Recovery setting	
Demographics	
Social support	
Missing Data	
Analytic Strategies	

Oualitative Data	
Study sample	
Study Sites and Method of Recruitment	41
Characteristics of settings	45
Nursing home	45
In home	46
Interview protocol	47
Data Analysis	
Interpretive Phenomenological Analysis	
Coding	
Combining the Qualitative and Quantitative Analysis	
IAPTER 4	
ESULTS	
Quantitative data	
Qualitative data	67
Primary and Sub-Primary Themes	69
Theme 1: Social Support Expectations and Perceptions	
Sub-theme 1a: Expectations of Social Support	71
1ai: Lack of consideration of social support	72
1aii: Self-reliance as expectation	72
1aiii: Expected use of technology	73
1 aiv: Expectations based on social network	73
1av: Expectations based on previous experience	74
1 avi: Lack of discussion as part of discharge	74
Sub-theme 1b: Perceptions of Social Support	75
1bi: Positive influence of social support	76
1bii: Different kinds of social support	
1biii: Perceived self-reliance	
1biv: Use of technology	
1by: Negative social support	
Theme 2: Differences Between Expectations and Perceptions	
Theme 3: Loneliness	
Theme 4: Themes Beyond Loneliness	
Sub-theme 4a: Choice of recovery setting	
4ai: Recovery setting assumptions	
4aii: Decision-making of others	
4aiii: Previous experience	87
4aiv: Discharge experience	
Sub-theme 4a: Hospital stay	
Sub-theme 4b: Ouestions about discharge	91
Interviewer Observation	92
Environmental Context	93
Perceived Socioeconomic status	93
[APTER 5	

DISCUSSION	
Research Questions, Secondary Data Analysis, and Thematic Interpretation	
Research question one	
Research question two	
Research question three	104
Rigor in Qualitative Data	107
Health Belief Model	108
Limitations	110
СНАРТЕК 6	114
CONCLUSION	114
Implications	114
Social Work Practice Implications	114
Educational Implications	118
Policy Implications	
Research Implications	123
Conclusion	125
APPENDICES	127
APPENDIX 1 - All IRB documents	128
APPENDIX 2 - HRS Data Variables used for Sample	
APPENDIX 3 - Scripts used at Site 1 and Site 2	135
APPENDIX 4 - Site 1 Consent	137
APPENDIX 5 - Survey Assessment.	141
APPENDIX 6 - Flyer and Letter for Site 2	148
APPENDIX 7 - Interview Documents	151
APPENDIX 8 - Sample Field Notes	164
APPENDIX 9 - Interviewer Reflection.	165
REFERENCES	166

# LIST OF TABLES

Table 1 Summary of enrollment sites	44
Table 2 Description of key study variables (n=3,798)	60
Table 3 Description of loneliness by setting	62
Table 4 ANOVA and Post Hoc tests of social support by setting	63
Table 5 Regression Models	65
Table 6 Interaction Models	67
Table 7 Demographic data from qualitative interviews	68
Table 8 Emotion, Social, and Overall Loneliness and Social Network	69

# LIST OF FIGURES

Figure 1 - Conceptual relationships using the Health Belief Model and social support research	28
Figure 2 - Health and Retirement Study sample and inclusion criteria	35
Figure 3 - Themes and sub-themes of qualitative data	70
Figure 4 – Montreal Cognitive Assessment (MOCA)	161

# **CHAPTER 1**

# **INTRODUCTION**

## **Statement of the Problem**

L. Frank Baum (1900) had it right in The Wonderful Wizard of Oz. Dorothy spent much of the book wishing to return home where she was comfortable and comforted. This sentiment is as true now as it has ever been. Home is where most individuals prefer to be discharged following a hospital stay (AARP, 2007). Older adults, who make up the majority of individuals discharged from the hospital, are sent home 65% of the time to recover. The assumption appears to be that going home is better than going to a nursing home for purposes of recovery from illness. These decisions, most frequently made by discharge planners with little to no input from the older adult, may be based on cost, where they believe physical recovery will happen best, or possibly from where they receive the first opening (nursing home or in-home care setting) (Popejoy, Moylan, & Galambos, 2009). When thinking about quality of life, however, there is little evidence to date that home is necessarily the best recovery setting.

Quality of life, specifically health related quality of life, is defined by the Office of Disease Prevention and Health Promotion (2017) as a multi-dimensional concept that includes aspects of physical, mental, emotional, and social functioning. One aspect of quality of life is loneliness. Loneliness is defined as the difference between the amount of social support you expect to receive and the amount you perceive you are getting (Peplau & Perlman, 1982). This definition distinguishes loneliness from the presence of people – that is, an individual can feel lonely in a crowd of friends or family or they can be alone and not experience loneliness. Similarly, in the context of recovery, the risk of loneliness is not just about whether a setting will provide contact with more people, but rather the older adult's expectations and perceptions of

support from the time of hospital discharge to the experience in the recovery setting. If an individual believes or expects that they will have many people, or particular types of support, surrounding them during their recovery and then once in the recovery setting believes they do not have that support, they are likely to be lonely. The opposite might also be true: if an individual believes or expects that they will be fine on their own or without particular types of support and if that is what they experience in the recovery setting they would likely not feel lonely even though they are alone. Therefore, the true measure of loneliness is the matching of expectation with perception. To date, the experience of loneliness has not been empirically tested across recovery settings.

The negative effects of loneliness on health are similar to the effects of smoking and obesity. A recently released study noted that loneliness is as detrimental to health as smoking fifteen cigarettes per day (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). Many of the interventions used to address loneliness have shown little positive result. This may be, in part, because they have focused on increasing the number of social supports surrounding the individual despite understanding that loneliness is more about the discrepancy between expectation and perception than numbers of social supports (Drageset, Espehaug, & Kirkevold, 2011; Heinrich & Gullone, 2006). It is this relationship between expectation and perception that

#### **Theoretical Framework**

The Health Belief Model (HBM) is a public health framework that has been used to understand health related behavior including smoking, vaccination, and HIV/AIDS. The model was developed more than 50 years ago and includes six areas: susceptibility to risk, severity of risk, perceived benefits, perceived barriers, self-efficacy, and cues to action (Becker, 1974;

Bylund et al., 2011). The first two areas, susceptibility to risk and severity of risk, have been described in previous research as the expectation one has regarding risk of a negative outcome related to health that includes both how likely it is that one is at risk and how bad the consequences would be if the risk occurs. Perceived benefits and barriers refer to what an individual believes they will get out of an action and how hard it will be to engage in the action. Finally, self-efficacy, as described by Bandura (2004), is an individual's belief in their ability to affect change in a situation. Cues to action are the knowledge and information an individual receives as they are confronted with a potential health decision. It is this model, framed by an understanding of social support, that guides this inquiry.

Social support is defined in the context of recovery as the professional and informal individuals (such as family and friends) on whom the recovering person relies for help. Social support includes both structural and functional dimensions. Structural support is defined as the number of individuals present or available to provide assistance (Cohen & Wills, 1985), sometimes referred to as the social network. Functional support is the individual's perception of the support they are receiving. It is the perception of functional support that has the most instrumental effect on health outcomes (Thoits, 1995). The discrepancy between what a person expects of their functional support and what they perceive they are getting is the definition of loneliness.

Social support has been found to moderate the relationship between stressful situations, such as hospital discharge, and health related quality of life (Cummins, 1988; Simon, Chang, Zhang, Ruan, & Dong, 2014). Within a Health Belief Model framework, social support may be a "cue to action", one of the factors influencing discharge decisions, in this case the choice of recovery setting. In the case of hospital discharge, research suggests that it is the discharge

planner who is serving to identify expectations of susceptibility and severity on behalf of, but with very little input from, the older adult. These decisions may be based, in part, on the assessment that social supports are available to the recovering older adult, but not on the older adult's expectation of support. If, after discharge, there is a discrepancy between the social support that was expected, and the older adult's perceptions of the social support actually received, this could result in loneliness. Discharge planning, therefore, plays a key role in this decision-making process and might be a potential point of intervention in addressing loneliness post-discharge.

The HBM has been used to design preventative health programs but has not been used to frame an understanding of either hospital discharge or loneliness. In this study, the HBM is being used as a framework to examine expectations of social support in the context of hospital discharge with the recognition that the person of interest – the older adult - has limited agency in this process. The discharge planner makes decisions about discharge based, in part, on her expectations of where the patient will receive the most, and the most relevant, support. This may or may not match patient expectations. An exploration of expectations before discharge and perceptions in the recovery setting will illuminate understanding of how what is expected differs from what is perceived, how this varies by recovery setting, and how it is related to loneliness during recovery.

### Significance of the Study

Despite an abundance of studies, the literature is mixed on whether a person has better physical health outcomes when recovering at home or in a nursing home. There is some evidence to suggest that individuals who recover at home do better or have similar recovery rates in their physical recovery as compared to those who recover in a group setting such as a nursing home

(Dalal, Zawada, Jolly, Moxham, & Taylor, 2010). However, studies of individuals recovering from cardiac illness indicate that persons living alone are at increased risk of reoccurrence of illness (Heffner, Waring, Roberts, Eaton, & Gramling, 2011; Herlitz et al., 1998). It is not clear from this research whether living alone has a negative effect because of loneliness, lack of practical social support such as transportation and help with household chores, or because living alone increases the likelihood of engaging in negative health behaviors. There is little in the literature about emotional or quality of life outcomes. By including psychosocial factors, such as expectation and perception of social support, it may be possible to identify their influence on the outcome of loneliness, a factor in quality of life and an influence on negative health outcomes.

Understanding loneliness in the recovery setting is important because empirical measures of loneliness have been linked to overall health outcomes across many disciplines (Cacioppo et al., 2000; Heikkinen & Kauppinen, 2011; Paul, Ayis, & Ebrahim, 2006). As stated earlier, House, Landis, and Umberson (1988) describe the effect of loneliness on health outcomes as like that of high blood pressure, obesity, and smoking. Shiovitz-Ezra and Ayalon (2012) demonstrated poor physical health and mortality as outcomes from chronic loneliness. Many empirical studies and meta-analyses have concluded that loneliness has a negative effect specifically on cardiac illness and recovery (Cacioppo et al., 2000; Cacioppo, Hawkley, & Thisted, 2010; Cacioppo & Patrick, 2008; Eng, Rimm, Fitzmaurice, & Kawachi, 2002; Hawkley, Burleson, Berntson, & Cacioppo, 2003; Hawkley, Masi, Berry, & Cacioppo, 2006; Holt-Lunstad, Smith, & Layton, 2010; Lett et al., 2005). While loneliness has often been studied as a cause of negative health outcomes, it makes sense to determine what situations influence the onset and duration of loneliness to develop targeted interventions. Because of the increased risk of cardiac illness as a person ages, a focus on cardiac patients' experience with loneliness in recovery is logical. This study uses mixed methods to explore the health behavior loneliness in two settings, nursing homes and in home. Demographics and specific types of social support are also explored for their influence on loneliness.

This study is significant in several ways. First, the project adds to the dearth of literature on both the outcome of loneliness for persons without cognitive impairment and the comparison of loneliness across two common recovery settings. Findings will inform ongoing debates around policies which encourage recovery in the home setting (Administration on Aging, 2004; AARP Public Policy Institute, 2009). Second, understanding the interaction between social support and recovery setting on the outcome of loneliness could inform discharge planning procedures. Discharge planners who assess risk of loneliness for their patients could better incorporate an understanding of the role of social support into their plan of care. Healthcare social workers in acute, nursing home, and home care settings could use social support measurement tools to identify relationship needs of clients before, during, and after recovery. Evidence provided by investigating these questions could add to the knowledge base of professional social workers. Third, the qualitative interviews will shed light on the ways in which older adults' expectations are or are not incorporated into discharge planning.

#### **Overarching Goal of the Study**

The overarching goal of this study is to better understand loneliness among older adults with cardiac illness in two settings - at home and in nursing homes. This mixed-methods study explores the following questions:

(1) How do individual reported levels of loneliness compare for older persons with cardiac illness who are at home versus in a nursing home?

(2) How do socio-demographic characteristics (age, gender, ethnicity/race, marital, and socioeconomic status) influence the patient reported levels of loneliness?

(3) How does perceived social support influence reported levels of loneliness?

These questions are explored through the theoretical framework of the Health Belief Model (Howard et al., 2016; Janz & Becker, 1984; Jurkowski, 2004) and using an understanding of social support (Leon-Perez, Wallston, Goggins, Poppendeck, & Kripalani, 2016; Umberson & Montez, 2010).

# **Organization of the Dissertation**

In addition to this introduction, the dissertation is comprised of the following chapters:

- Chapter Two: A literature review that connects recovery setting and loneliness using the Health Belief Model in a framework of Social Support.
- Chapter Three: The methodology used, including both quantitative and qualitative research procedures, sampling, survey design, interview protocols, and the data analysis method.
- Chapter Four: Findings from both the quantitative and qualitative data analysis.
- Chapter Five: Discussion and the limitations of the study.
- Chapter Six: Implications for social work practice and policy, as well as possible directions for future research.

#### **CHAPTER 2**

# LITERATURE REVIEW

This chapter looks at the literature that is most relevant to the issues of loneliness and recovery setting. The guiding theoretical model is presented, as are descriptions of each construct included in this research.

## Theory

This inquiry into the intersection of loneliness and recovery setting is guided by the Health Belief Model and previous research on social support. The Health Belief Model (HBM or the Model) is a public health theory developed more than fifty years ago. The HBM emphasizes the need to understand and define health behaviors, and identifies the roles of both health care systems and providers. The HBM includes elements of the definition of loneliness, specifically expectations and perceptions, and helps illustrate how older adults and health care providers make decisions regarding recovery setting. Application of the Model to an understanding of loneliness as a health behavior appears to be unique. Using the Model, along with previous research on social support, may help in understanding how loneliness occurs and may provide guidance in addressing loneliness as a public health concern.

#### **Health Belief Model**

The Health Belief Model (HBM) is a public health framework used to explain health related behavior. The HBM was developed in the 1950's and is one of the most widely used frameworks to explain and predict health behavior (Gochman, 1997; Jopling, 2015). The HBM is a psychological and social cognitive theory. It was originally used to explain individual responses to symptoms, diagnoses, and compliance with prescribed medication (Hochbaum, 1958; Rosenstock, Strecher, & Becker, 1988). It has been used in both prospective and

retrospective studies to explain health behavior (Harrison, Mullen, & Green, 1992; Kim & Zane, 2015; Mo, Chong, Mak, Wong, & Lau, 2016; Saunders, Frederick, Silverman, & Papesh, 2013). Public health campaigns designed to decrease smoking, increase mammograms, and flu vaccines and many other health related areas have used the tenants of the HBM to understand and modify health behavior.

The Model uses a well-researched definition of health behavior. Health behavior is defined as:

Those personal attributes such as beliefs, expectations, motives, values, perceptions and other cognitive elements...that relate to health maintenance, to health restoration, and to health improvement. (Gochman, 1997, p.3)

Health behavior is both objective and observable as well as subjectively reported by the individual. Health behavior research is about expectations and perceptions rather than treatments, health delivery, and outcomes. In this regard, loneliness fits the definition of health behavior with the inclusion of both expectation and perception.

The Health Belief Model focuses on the systematic assessment by health professionals of expectations and perceptions to predict individual behavior (Rosenstock, 1974). Health professionals play a significant role in determining health behavior, not only through assessment, but also when they provide information and education to their patients (Gochman, 1997). Health behaviors are influenced by personal beliefs or perceptions about a health concern and knowledge of strategies available to decrease the occurrence of the health concern (Hochbaum, 1958).

Current use of the Model is informed by a psychological approach designed to change individual thinking (Jopling, 2015). Stretcher, Champion and Rosenstock (1997) summarize the HBM by stating:

It is now believed that individuals may take action to ward off, to screen for, or to control ill health conditions if they regard themselves as susceptible to the condition, if they believe it to have potentially serious consequences, if they believe that a course of action available to them would be beneficial in reducing their susceptibility to or the severity of the condition, and if they believe that the anticipated barriers to (or costs of) taking the action are outweighed by its benefits (p. 73).

The Health Belief Model includes three main areas:

- Perceived susceptibility a person's belief that the health issue is relevant and/or their diagnosis is correct.
- Perceived threat a person's belief that, even if they may be susceptible, the health issue is bad enough to have serious physical, mental, or social consequences.
- 3. Perceived benefit vs. perceived barriers a person's belief that a health behavior may result in a positive outcome and that the effort may not be too difficult (Hayden, 2014).

Other variables are present in the Model including self-efficacy, sociodemographic

factors, and cues to action (Hayden, 2014). Self-efficacy, an individual's belief in their ability to make a difference in their own health outcomes, is an overarching concept in the Health Belief Model and influences the three main areas. Other variables, specifically sociodemographic factors such as educational attainment, may have an indirect effect on behavior by influencing perception. For example, a person who can read may better understand their health situation by self-informing on the diagnosis; this would then influence their perception about the health concern. Cues to action include both external information given (health education) and a person's own feelings about their diagnosis and prospects for recovery.

Of the constructs included in the Model, perceived susceptibility is one identified as having a strong influence on health behavior (Hayden, 2014). When an individual perceives that they are at risk, HBM research indicates that positive health behaviors are more likely. The parallel to loneliness is that expectations of social support speak to perceived susceptibility or risk. If an individual believes that they may receive the support they need, they likely see no possibility of loneliness. This supposes that the older adult thinks about this issue at all, an idea that is unclear. More likely, discharge destination or recovery setting is a decision made by health care providers, specifically the hospital discharge planner. As noted by Gochman (1997), health professionals play a central role in determining health behavior outcomes for patients. This study will shed additional light on the role health professionals and others have during discharge and if loneliness is a consideration in discharge planning.

Previous research has noted the need to assess health behaviors using the Health Belief Model (Rosenstock, Strecher, & Becker, 1988). By understanding individual expectation and perception related to health behaviors, including those associated with serious health consequences, there is a higher likelihood that needed change could be understood and effected. Self-efficacy is the area in the model, along with cues to action, which may hold the most promise for individual change through education and empowerment (Rosenstock, Strecher, & Becker, 1988). This aspect of the Health Belief Model, a person's potential ability to feel empowered to change their health behavior, in this case loneliness, is one of the strengths of the use of this model in this inquiry.

## Loneliness

Loneliness is a subjective, self-reported discrepancy between how much social interaction an individual wants and how much they believe they have (Peplau & Perlman, 1982). Loneliness is considered, using various measures, as existing on a continuum from not lonely to extremely lonely (De Jong Gierveld & Kamphuis, 1985; Russell, Cutrona, & Wallace, 1997; Russell, Peplau, & Cutrona, 1980). Research is not clear on how extreme loneliness must be to be considered detrimental to physical and mental health. In general, if a person indicates that they are lonely, through saying they are lonely (direct measure) or indicating any level of loneliness on a valid scale (indirect measure), then they are considered lonely for purposes of intervention and indication of negative health outcomes. Given the definition of loneliness in the previous studies, throughout this review of the literature and this research inquiry the term 'loneliness' will be used to denote individually reported experiences of loneliness at any level.

Early reports of the concept of loneliness began with description only and treating it as interchangeable with anxiety, depression, and social isolation (Freud, 1920; Fromm-Reichmann, 1959). Later empirical inquiry was epitomized by continued conflation of loneliness, social isolation, and depression that confused the understanding and treatment of all three constructs. More recent research has focused on the measurement of various constructs of loneliness, the impact loneliness has on negative health outcomes, and the need to treat loneliness as a public health crisis (Drageset, Espehaug, & Kirkevold, 2011; Heinrich & Gullone, 2006; Jaremka, et al., 2014; Schoenmakers, Van Tilburg, & Fokkema, 2014). This understanding of the history of loneliness in the literature and the difference between loneliness, social isolation, and depression, may help meet the requirement outlined in the Health Belief Model, that of needing to

understand a health behavior to best address change in the health behavior. To distinguish loneliness from social isolation and depression, and to ensure that the focus of this study remains specifically on loneliness, a brief description of how loneliness differs from the other two constructs is helpful.

Social isolation is an objective measure of companionship or social connectedness (Hawthorne, 2006). Social isolation has been defined in terms of the number and types of interactions in an individual's social network (Cobb, 1976; Cornwell & Waite, 2009; Grenade & Boldy, 2008; Umberson & Montez, 2010; Zimet, Powell, Farley, Werkman, & Berkoff, 1990). Social isolation is described as the opposite of social support (physical or emotional assistance given by one person to another (Molineux, 2017). Social isolation is often measured by counting the number of people an individual has in their social network. While knowing the number of contacts an individual has may shed light on their resources, it does not tell anything about the quality of those relationships and whether they have a positive or negative influence. Given that loneliness is more about how social relationships are perceived, identification of numbers does not measure loneliness. In distinguishing loneliness from social isolation, Hawkley, Burleson, Berntson, & Cacioppo (2003) measured the differences in social contact between those who selfdescribed as lonely and non-lonely. Findings indicate that there is little difference in the number of social contacts between these groups, indicating that loneliness and social isolation, while related in some cases, are not the same thing.

Depression is another construct often conflated with loneliness. Depression is used in common parlance as a term for sadness and is also a diagnosed mental health condition (American Psychological Association, 2000). Empirical studies of depression are complicated by the different types and symptoms of depression. Studies often do not use the same measurement

tool or the same operational definition of depression. Klug et al., (2014) identified numerous studies which have contradictory findings about the prevalence of depression in persons over the age of 60. Depression and loneliness, while sharing some common predictors, have been shown to be different constructs (Steptoe, Owen, Kunz-Ebrecht & Brydon, 2004; Weeks, Michela, Peplau & Bragg, 1980). Cacioppo, Hughes, Waite, Hawkley, and Thisted (2006) measured both constructs, depression and loneliness, and determined that each, while related, can be treated as separate items. Not all older adults who experience loneliness are depressed (Perlman & Peplau, 1984). This evidence suggests the need to measure loneliness and depression separately to be sure both variables are considered independently. Modern research into loneliness has addressed these earlier studies by separating the constructs of loneliness, social isolation, and depression. However, it has taken some time for this to occur.

**Previous loneliness research**. Early inquiry into loneliness focused on diagnostic aspects of the health behavior. Loneliness was linked to feelings of anxiety, aloneness, and depression (Freud, 1920; Gero, 1936). Much of the writings on loneliness in the early 20<sup>th</sup> century echoed Freudian language of separation and longing (Fromm-Reichmann, 1959; von Witzleben, 1958; Winnicott, 1958). The relationship to anxiety was described by Freud (1920) as something that results when one is separated from others. Zilboorg (1938) discusses loneliness in terms of narcissism (another Freudian concept) and feelings of being alone. Other writings describe the process of being alone as psychologically untenable and requiring intervention to achieve good mental health (Winnicott, 1958). Although Greer (1953) clearly differentiated between loneliness and social isolation, this separation in the constructs was not common in early psychiatric and medical research (Fromm-Reichmann, 1959; Peplau, 1955; von Witzleben, 1958; Zilboorg,

1938). These authors describe anecdotal observations of loneliness by the patient and the practitioner rather than engaging in empirical inquiry (Wood, 1953).

Empirical research on loneliness is found in literature starting in the 1960's (Peplau & Perlman, 1982). Loneliness was linked to overall health outcomes including both mental (Heikkinen & Kauppinen, 2011; Paul, Ayis, & Ebrahim, 2006) and physical health (Cacioppo et al., 2000). Specifically, loneliness was measured as a contributing factor to poor health outcomes following cardiac illness (Eng, Rimm, Fitzmaurice, & Kawachi, 2002; Lett et al., 2005). Authors have used multiple definitions of loneliness (Gerst-Emerson & Jayawardhana, 2015; Hawkley & Cacioppo, 2003; Klein, 1963; Peplau & Perlman, 1982; Weiss, 1973) with more recent investigation of loneliness focusing on an individual's subjective experience, separating the experience of loneliness from social interactions. Peplau and Perlman (1982) defined loneliness as a "discrepancy between one's desired and achieved levels of social interaction" (p. 31). This definition is seeded throughout modern empirical research on loneliness.

Most research on loneliness from the past twenty years defines the concept as one that is a perception by the individual, a subjective experience. Hawkley, Masi, Berry, and Cacioppo (2006) describe loneliness as a "gnawing" (p. 152) emotional state "without redeeming features" (p. 152). The identification of loneliness as a perceived experience by an individual is common in the literature today (Drageset, Espehaug, & Kirkevold, 2011; Heinrich & Gullone, 2006; Jaremka, et al., 2014; Schoenmakers, Van Tilburg, & Fokkema, 2014). Hawkley, Masi, Berry, and Cacioppo (2006) use terminology that describes feelings associated with loneliness. Using the definition offered by these authors, loneliness is measurable only by an individual saying he or she feels lonely.

According to Pikhartova, Bowling, & Victor (2016) there are two aspects of loneliness: one is emotional, the other is social. The emotional aspect revolves around feelings or perception (the self-reported, direct measure of loneliness) and has been conflated with depression, a separate construct (Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006). This emotional aspect is how a person feels about the relationship(s) they do or do not have with others. The social aspect of loneliness is the number of relationships the individual wants to have. It is related to social isolation, but distinct in that its focus is on the perception of a desirable number of relationships rather than on the objective number of existing relationships. Pinquart and Sorensen (2001) identify the difference between the emotional and social aspects of loneliness as a feeling of suffering and disconnection between the relationships one has and the relationships one wants to have. Their definition helps to clarify how a person can be socially isolated (technically have very few social interactions or relationships) and not feel lonely (Pinquart & Sorensen, 2001) or feel lonely with many social interactions or relationships. This discrepancy between desire and perception is also a common feature in empirical measurement of loneliness (Donaldson & Watson, 1996; Gerst-Emerson & Jayawardhana, 2015; Theeke & Mallow, 2013).

**Measurement of loneliness**. Loneliness is a latent construct which cannot be observed. The measurement of loneliness must take place using subjective means through the report of the individual being studied. Heinrich and Gullone (2006), in their review of the empirical literature on loneliness, noted that while some question the reliance on self-report, because of the subjective nature of loneliness, self-report is the most defensible measure. Indicators of loneliness include both emotional and social constructs (Heinrich & Gullone, 2006; Weiss, 1973). Emotional loneliness includes indicators such as a lack of a confidant or close personal relationships (Russell, Cutrona, Rose, & Yurko, 1984; Weiss, 1973). Social loneliness is typified

by fewer social contacts or a smaller social network (Russell, Cutrona, Rose, & Yurko, 1984; Weiss, 1973). Both indicators are measured in empirical studies, often through different means. Direct questions about loneliness and indirect measures of indicators of loneliness are used.

Direct measurement of loneliness is accomplished using a one-item question that asks if loneliness has been experienced in the recent past (Luo & Waite, 2014; Shiovitz-Ezra & Ayalon, 2012). This is considered direct measurement because it uses the word lonely or loneliness in the question. This measure has been used in much of the research on loneliness (Luo & Waite, 2014; Pinquart & Sorensen, 2001). Pinquart and Sorensen (2001) conducted a meta-analysis of loneliness research and found, in more than half of the studies reviewed, that a single-item question directly asking about the frequency or intensity of the experience of loneliness was used. However, there are difficulties with this direct approach to measuring loneliness. Older adults may be unwilling to admit to being lonely, perhaps due to social stigma and other negative social repercussions (Holmen, Ericsson, Andersson, & Winblad, 1992; Shiovitz-Ezra & Ayalon, 2012; Victor, Scambler, Bond, & Bowling, 2000). Acknowledgement of this concern for underreporting of loneliness has led to more research using indirect measures. It is important to note that direct measure of loneliness has been correlated with scores of loneliness on indirect measures (Luo & Waite, 2014; Shiovitz-Ezra & Ayalon, 2012).

This indirect approach to measuring loneliness is increasingly common in the empirical literature (De Jong Gierveld & Kamphuis, 1985; Ebesutani et al., 2012; Nicolaisen & Thorsen, 2014). The Revised UCLA Loneliness Scale (R-UCLA) (Russell, Cutrona, & Wallace, 1997; Russell, Peplau, & Cutrona, 1980) is an example of the indirect approach. The R-UCLA has been widely used in research on loneliness in older adults (Cacioppo, Hawkley, & Thisted, 2010; Steptoe, Owen, Kunz-Ebrecht, & Brydon, 2004; VanderWeele, Hawkley, Thisted, & Cacioppo,

2011). The R-UCLA has also been modified to a three-item scale used in large population samples such as the HRS data used for the quantitative portion of this study. Previous research on the three-item scale have found it to have adequate psychometric properties (Cronbach's  $\alpha$ =.72) and note that it measures only one aspect of loneliness and is considered a unidimensional measure of loneliness (Shiovitz-Ezra & Ayalon, 2012).

The idea that loneliness is a one-dimensional construct is not fully accepted by the empirical research community. Weiss (1973) described loneliness as having two constructs, emotional and social. Many others have also described loneliness this way (Heinrich & Gullone, 2006). However, even those researchers who adopt Weiss's (1973) two-dimensional construct, have used unidimensional measurements of loneliness, both direct and indirect. The 3-item measure of loneliness adopted from the R-UCLA scale (Hughes, Waite, Hawkley, & Cacioppo, 2004), does not make Weiss's (1973) distinction between social and emotional loneliness. The de Jong Gierveld Loneliness Scale (De Jong Gierveld & Kamphuis, 1985) measures loneliness indirectly through questions about both the social and emotional aspects of loneliness. The indirect questions include ratings of feelings of emptiness and rejection as well as the amount and quality of the relationships an individual perceives. The scale is based on loneliness being two-dimensional and measures both the emotional and social aspects of loneliness (Nicolaisen & Thorsen, 2014). Comparisons of direct measure of loneliness (asking a person if they are lonely) and the indirect measure using both unidimensional and multidimensional measurement of loneliness, have been made in empirical studies and have been found to identify loneliness equally well (Nicolaisen & Thorsen, 2014; Victor, Grenade, & Boldy, 2005).

The direct and indirect measures of loneliness mentioned above address only the perception a person has of their current situation with regards to self-reported feelings and

identification of social support (companionship and isolation from others). None of the loneliness measures address an individual's expectations of social support directly, a key part of the definition of loneliness. Wanting more or better-quality relationships with others, stronger social support, and/or perceptions that the social support you are receiving is not enough, is the definition of loneliness. A better understanding of what social support is, measurement of social support separately from loneliness, and understanding what role social support plays in the lives of older adults gives more insight into the experience of loneliness.

#### **Social Support**

Social support has been defined in multiple ways in the literature. Dong, Beck, and Simon (2009) describe social support as the availability or perception of availability of people on whom a person can rely. Bell and Gonzalez (1988) identify social support in terms of the availability of people who can be relied upon or make known that they care. Mankowski and Wyer (1997) and others (Chronister, 2009; Dong, Beck, & Simon, 2009; Nausheen, Gidron, Gregg, Tissarchondou, & Peveler, 2007) separate the perception (function) of social support from measurement of actual (or structural) social support. Structural support is described as the network of social relationships and the density of those relationships (Chronister, 2009).

Mankowski and Wyer (1997), in separating structural support from functional support, are clear that perceived support is the modifying influence on overall well-being. Perceived support, how an individual identifies the impact of the help they receive or have available, is the definition which is most closely tied to positive overall well-being (Procidano & Smith, 1997). Perceived support also mirrors an aspect of loneliness, namely that when a person perceives deficits in the quality of support available to them they self-report as being lonely (Peplau &

Perlman, 1982). Operationalizing perceived social support in terms of its moderating influence on loneliness is central to much of the literature on social support.

Cobb (1976) proposed a theory of social support which places the role of social support as a moderator of stressful life events. There is a breadth of literature on social support as a theoretical construct, however there are many discrepancies and disagreements in the application of the theory to help inform an understanding of how and why social support moderates stress (Rook & Dooley, 1985). Social support is a mechanism which allows a person to cope with crisis and adapt to change (Chronister, 2009; Cobb, 1976). Comijs, Penninx, Knipscheer, and Van Tilburg (1999) suggest that greater social support might have a moderating effect on psychosocial distress (feelings of sadness, anxiety, etc.). Other studies found that social support may modify self-reported loneliness (Comijs, Penninx, Knipscheer, & Van Tilburg, 1999; Dong, Beck, & Simon, 2009). Litty, Kowalski, and Minor (1996) found that individuals perceive stressful situations in different ways depending on the amount of social support they believe they have. This perception of stressful life events, facilitated by interactions with others, may be the mechanism by which social support moderates the relationship between recovery setting and loneliness.

Measurement of social support is accomplished in multiple ways. Existing literature on social support use multiple measures, including validated scales. Social support is not only a construct defined by the number of individuals in a person's social network, but also by the quality of relationships. Therefore, measurement must include both numbers and quality. Cohen (2004) in studying the relationship between social support and health, measured both the quality and function of social support in positive and negative ways. This research and others (Uchino, 2009) led to the development of a perceived social support scale that identifies both positive and

negative social support. Lubben et al. (2006) developed a scale of social network which has been used to measure social support. In a study of cardiac patients following hospitalization, Baigi, Hildingh, Virdall, and Fridlund (2007) found that social support was needed to a greater extent after than prior to hospitalization and that professionals play a role in supporting both patients and families. While there are no known studies which compare the perceived social support scale and the Lubben Social Network scale, both have been used to measure social support and are considered measures of perceived social support (Baigi, Hildingh, Virdall, & Fridlund, 2008; Lubben & Gironda, 2004).

Previous literature calls for continued research on the moderating effect of social support and the need to study the moderating influence of social support between life events such as the need for nursing home placement or the use of home care and psychosocial outcomes (including loneliness) (Cobb, 1976). It is this call for action on understanding expected and perceived social support (the definition of loneliness) that ties the Health Belief Model and the health behavior of loneliness together. It is also an increasing understanding of social support and loneliness in recovery settings that might lead to interventions to address loneliness.

#### Life Transitions

Life events, such as institutionalization, illness, and role changes based on aging, are triggers for loneliness (Pinquart & Sorensen, 2001; Schoenmakers, Van Tilburg, & Fokkema, 2014). Limited mobility and competence in activities of daily living have also been associated with increased risk of loneliness as well as triggering the need for increased professional care which can be received at home (Victor, 2015). This study will look specifically at the relationship setting has on loneliness.

**Recovery setting**. The care of older adults has a long narrative in history. Historically, care for older adults was provided by family members, neighbors, and local communities (Gold & Kaufman, 1970). The Centers for Disease Control and Prevention (CDC) (2013) define long-term care services as those including "health, personal care, and supportive services" (para 1) that provide assistance in dressing, bathing, medication management and other health maintenance tasks. The goal of long-term care is to maintain and improve physical function and quality of life (CDC, 2013). While persons of all ages use long-term care services, it is estimated that more than two-thirds of all persons over the age of 65 need some form of long-term care services (CDC, 2013). Persons over the age of 85 will almost triple in the next thirty years (Ortman, Velkoff, & Hogan, 2014), and will continue to make up a large majority of individuals who use long-term care services (CDC, 2013).

Long-term care services in Michigan can be provided in several settings, including licensed long-term care facilities (nursing homes), unlicensed assisted living facilities, and care in the home (or in-home care). Nursing homes in Michigan range from private care only to skilled nursing care to hospital-setting Medicare units (Department of Licensing and Regulatory Affairs, 2016). This continuum of institutional long-term care services includes more and less home-like environments, all of which provide care under Federal and/or State law (Department of Licensing and Regulatory Affairs, 2016). In-home care services are distinguished by the service provider coming to the older adult to provide care (Centers for Medicare & Medicaid Services, 2016). These services can include direct care workers, physician, nursing, physical and occupational therapy, social work, pastoral care and a variety of homemaking and friendly visitors (Centers for Medicare & Medicaid Services, 2016).

More than half of all older adults discharged from hospitals today go home (Healthcare Cost and Utilization Project (HCUP), 2010b). While most older adults express a desire to return home, previous research suggests that much of the discharge decision making is done by professionals rather than older adults themselves (Brown, 1997; Popejoy, Moylan, & Galambos, 2009). The limited evidence on where older adults wish to recover appears to come from research focused on older adults' desire to 'age in place' (Administration on Aging, 2004; Kwon, Ahn, Lee & Kim, 2015).

Aging in place is defined by the Centers for Disease Control and Prevention (CDC) (2013) as "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level" (para. 5). While the concept of aging in place has some relevance to a discussion about choice of recovery setting following an acute hospital stay, the literature on aging in place does not address this choice specifically. The empirical evidence that older adults wish to remain in their own homes does not translate directly to a specific desire to recover at home following a hospital stay given the complexity of need following a discharge (Administration on Aging, 2004; AARP Public Policy Institute, 2009). These complexities are not specifically addressed in the aging in place literature reviewed (Cutchin, 2003; Kwon, Ahn, Lee & Kim, 2015; Timmermann, 2012; Warner Schae, Wahl, Mollenkopf & Oswald, 2003; Venes, 2013). Yet health care policy, including Medicare and Medicaid funding, are dominated by calls for persons to recover at home; with in-home care being the preferred long-term care service (Popejoy et al., 2015; Szanton et al., 2015). These policy decisions appear to be the result of financial considerations rather than those related to an individual's quality of life (Brown, 1997; Popejoy, Moylan, & Galambos, 2009; Qian, Russell, Valiyeva, & Miller, 2011).

Upon discharge to a recovery setting, expectations of social support become reality, sometimes with negative consequences (AARP Public Policy Institute, 2009). Popejoy, Galambos, & Madsen (2012) found that patients discharged from the hospital with expectations of high levels of social support did not necessarily receive it. Lett, et al., (2005) conducted a review of previous empirical research on social support and cardiac illness. Findings indicated that social support is an important factor in recovery (Lett, et al., 2005). Multiple studies have found that feelings of loneliness and decreased social support, were related to higher rates of hospital readmission (Hutchinson et al., 2015). Recommendations from these studies identified the need for evaluation of loneliness and social support be a part of discharge planning and case management. Others have called for this emphasis on addressing expectations and psychosocial factors upon hospital discharge and to use these in decision making for recovery setting (Huber & McClelland, 2003). Hines, Barrett, Jian, and Steiner (2014) identify reducing risk of readmission as one of the goals of discharge planning. Because feelings of loneliness are associated with increased risk of adverse health outcomes, it may be important to consider loneliness assessment as a part of the discussion as older adults face hospital discharge. This appears to be one of the keys to potential reduction in hospital readmission.

Persons discharged from the hospital, no matter the recovery setting, are at risk for increased negative psychosocial issues, including loneliness (Foss & Hofoss, 2011; Qian, Russell, Valiyeva, & Miller, 2011; Walsh et al., 2012). In addition, it appears that there is a distinct relationship between loneliness and a greater risk for chronic illness (Cacioppo & Patrick, 2008; Thurston & Kubzansky, 2009). Rates of loneliness while recovering in a nursing home have been the focus of research. In a study of more than 200 cognitively intact nursing home residents, more than half reported feeling lonely (Drageset, Kirkevold, & Espehaug, 2011).
Limited evidence suggests that persons in nursing homes are lonelier than, or equally lonely to, those in the community (Nikmat, Hawthorne, & Al-Mashoor, 2015). This is consistent with the definition of loneliness as related to expectations about social contact, rather than quantity of social contact. Drageset, Kirkevold, and Espehaug (2011) identify a lack of research comparing loneliness as an outcome for cognitively intact older adults living in nursing homes versus receiving care in the home.

**Sociodemographics**. As individuals age, they experience many changes. Transitions in roles, income, and social network (including marital status) have been studied extensively in many contexts, including loneliness (Luhmann & Hawkley, 2016; Rico-Uribe et al., 2016; Theeke, 2009). The overall trend of previous research indicates that persons who are older, of lower socioeconomic status, female, single or widowed, and living alone are at the greatest risk for experiencing loneliness. Luhmann and Hawkley (2016) studied persons over the age of 80 and found that marital status and social support were significant predictors of loneliness. There were similar findings in other studies (Perlman, 1990; Pinquart & Sorensen, 2003) that lead to the conclusion that while age does not guarantee loneliness, age is associated with changes in roles, income, and social network, which do have a direct relationship with loneliness (Cohen-Mansfield, Hazan, Lerman, & Shalom, 2016). Pinquart and Sorensen (2003) found that women were more likely to be lonely, particularly those in a nursing home. Yet other studies have found men to experience increased loneliness (Drageset, Espehaug, & Kirkevold, 2011). This discrepancy may be in how men and women view social support, with men finding much of their support through their spouses and women finding relying on other means of social support (de Jong Gierveld, 2004; Warner & Adams, 2015). Studies of socioeconomic status using various

measures including household income, education, and subjective identification, have found a relationship with loneliness and social support.

Other sociodemographic characteristics have also been studied in relationship to the influence of social support on loneliness. Studies of race and ethnicity found social support to be a factor in health behaviors among persons of color (Rees, Karter, & Young, 2010). Persons who are Hispanic are less likely to be lonely than other ethnicities (Emerson & Jayawardhana, 2015). The size of the social network, which often decreases with age, was found to impact loneliness, with smaller social networks increasing the risk of loneliness (Cohen-Mansfield, Hazan, Lerman, & Shalom, 2016). Living alone has been found to influence loneliness, with persons living alone in the community being more likely to experience loneliness than those not living alone (Cohen-Mansfield, Hazan, Lerman, & Shalom, 2016; Pinquart & Sorensen, 2003). Finally, while cardiac illness is not specifically a sociodemographic characteristic, it is the most common reason for hospital admission for persons over the age of 65 in the United States and accounts for a large portion of the case load of hospital discharge planners (Greer, Nwaise, & Casper, 2010; HCUP, 2010a). Loneliness has been studied with cardiac patients and findings indicate that loneliness is a contributing factor to negative health outcomes following cardiac illness (Eng, Rimm, Fitzmaurice, & Kawachi, 2002; Lett et al., 2005).

#### Loneliness, Social Support, Life Transitions, and the Health Belief Model

Current treatment of loneliness is accomplished on a case-by-case basis with many interventions geared toward adding people, or social support, to address the problem. When an individual is identified as being lonely, another person is sent to spend time with them (Cacioppo, Grippo, London, Goossens, & Cacioppo, 2015; Masi, Chen, Hawkley, & Cacioppo, 2011). If loneliness is a community concern, programs like 'Friendly Visitors' are developed

(Personal conversation with Annette Jeske, Region VII Area Agency on Aging, June 13, 2017). Holt-Lunstad, Smith, Baker, Harris, and Stephenson (2015) found that increased interactions with people may address social isolation, but may not address feelings of loneliness. These approaches appear to fail to address the key components of loneliness when framed by the Health Belief Model and an understanding of social support, specifically, a person's perception of their risk for loneliness, their expectations about social support and their perceptions of social support during recovery. This failure reinforces the idea, posited by the Health Belief Model, that interventions are developed without understanding the health behavior itself. By attending to older adults' expectations and perceptions of social support, interventions for loneliness may be targeted to an older adult's knowledge and understanding (cues to action) of their risk, thus potentially changing their health behavior. Figure 1 illustrates the relationships among the constructs in this inquiry.



Conceptual relationships using the Health Belief Model and social support research

Overall health is not a part of this inquiry, however there is a relationship between loneliness and overall health.

Figure 1 - Conceptual relationships using the Health Belief Model and social support research

## **Study Methods**

From single-case studies to population surveys, the methods used to study loneliness vary in their focus and rigor. Initial research on loneliness was conducted as single-case studies. Freud (1920), Gero (1936) and Zilboorg (1938) all describe individual client experience and their observation of causes and repercussions of loneliness. Empirical research studies with increased rigor became more common in the 1960's (Peplau & Perlman, 1982). As measures of loneliness were validated with different populations, these more rigorous tools were used in larger, population based research studies such as those conducted by Ayalon and Shiovitz-Ezra (2011), Hand et al., (2014) and Musich, Wang, Hawkins, and Yeh (2015). Secondary data analysis is a common method of loneliness research and has been used extensively in the US and abroad (Ayalon & Shiovitz-Ezra, 2011; Luo & Waite, 2014; Maes, Klimstra, Van den Noortgate, & Loossens, 2015; Thurston & Kubzansky, 2009). These methods have been well accepted with results used in later studies confirming the presence of loneliness in a wide range of populations. These larger empirical studies have been generalized to older adults in long-term care and community settings, who have different health concerns, and who are from many different backgrounds (Luo & Waite, 2014; Maes, Klimstra, Van den Noortgate, & Loossens, 2015).

Sampling techniques vary from probability sampling in large, population based studies and smaller, community based research to non-probability techniques such as convenience and purposive sampling (Andersson, 1985; Chan, Anstey, Windsor, & Luszcz, 2011). Luo, Hawkley, Waite, and Cacioppo (2012) used a cohort from the Health and Retirement Survey, randomly selected, to answer questions about loneliness. Non-probability sampling techniques used include convenience sampling (Alpass & Neville, 2003; Bondevik & Skogstad, 1998; Bryan, Baker, & Tou, 2015; Ng & Northcott, 2015) and purposive sampling (Azeem & Naz, 2015; Theeke, 2009; Van Beljouw et al., 2014).

Larger studies using probability samples and quantitative techniques can provide an initial understanding of issues such as loneliness. However, almost all of the studies mentioned in this chapter called for additional research to understand causality and to ask questions of why loneliness occurs (Ayalon & Shiovitz-Ezra, 2011; Beswick et al., 2008; Luo, Hawkley, Waite, & Cacioppo, 2012; Luo & Waite, 2014). Quantitative results informed by the depth of meaning and

understanding found in qualitative studies brings a more comprehensive insight into the experience of loneliness.

Qualitative inquiry into loneliness has been used in multiple research studies and using many different methods of evaluation. Bonifas, Simons, Biel, & Kramer (2014) used phenomenology to understand what it was like for older adults in long-term care to experience changes in social relationships. Magilvy and Congdon (2000) used an ethnographic approach to study transitions of older adults in rural areas of the United States. Qualitative inquiry in loneliness research, is often paired with quantitative methods, typically scales which have been validated through rigorous methods (Rico-Uribe et al., 2016; Stokes, 2016; Van Tilburg, Dykstra, Liefbroer, & Van Groenou, 2003). Even in some of the secondary data analyses, openended questions asked in large scale surveys have been used to better understand the lived experience of loneliness (Wenger & Burholt, 2004). None of these methods are without limitations.

Vaux (1988) identified several design issues related to social support research which also speak to issues in research on loneliness. Much of the research on loneliness is cross-sectional, introducing the problems of reverse causation and spuriousness (Gottlieb, 1978; Hand et al., 2014; Penning, Liu, & Chou, 2014; Warner & Adams, 2016). Longitudinal studies (Greaves & Farbus, 2006; Hughes, Waite, Hawkley, and Cacioppo, 2004; Wenger & Burholt, 2004), while helpful in addressing issues of causation, do not necessarily rely on theoretical exploration of loneliness and social isolation as separate constructs. By designing research which adheres to theoretical models, including potentially influential variables (such as social support and demographic characteristics), and by using tested data analysis techniques, some of these problems might be addressed.

# **Importance of this Study**

This study addresses loneliness as a health outcome influenced by setting (nursing home or in home). The influence loneliness has on health outcomes is significant and with current policy focused on sending older adults back to their homes after a hospital stay, it is necessary to understand if setting influences the health behavior of loneliness. There is a distinct gap in the literature related to both loneliness and settings that this study attempts to fill. The inclusion of only individuals with no cognitive impairment, individuals who may be better able to identify their own expectations and perceptions, will provide more information that may help older adults, discharge planners, and policy makers who are faced with decisions on where older adults are least likely to be lonely.

Loneliness as a health outcome. While health outcomes related to loneliness are not the focus of this review of the literature, nor of the research inquiry developed and described herein, the relationship between loneliness and health outcomes underlies the significance of this study. There is no question that the individual experience of loneliness has a negative impact on health outcomes. House, Landis, and Umberson (1988) describe the effect of self-reported loneliness on health outcomes as like that of high blood pressure, obesity, and smoking. In a study from Brigham Young University (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015), loneliness was associated with an increased likelihood of mortality which is like the health risk of smoking fifteen cigarettes per day. Shiovitz-Ezra and Ayalon (2012) demonstrated poor physical health and mortality as outcomes from loneliness. Many empirical studies and meta-analyses have concluded that loneliness has a specific negative effect on cardiac illness and recovery (Cacioppo, Hawkley, & Thisted, 2010; Holt-Lunstad, Smith, & Layton, 2010; Valtorta,

Kanaan, Gilbody, Ronzi, & Hanratty, 2016). Loneliness as a health behavior, as defined previously, also plays into the more recent calls to treat loneliness as a public health issue.

In making an argument that loneliness is a health behavior that warrants a public health level of attention, it is important to understand how other health behaviors, with risk of death like that of loneliness, have been treated. The Centers for Disease Control (2014), in an analysis of US population data from 2005 – 2013, identify numerous health indicators, including obesity, substance abuse, and access to health care, as necessitating public health intervention. A review of research on loneliness concluded that loneliness increased risk of death by more than 26% (Hold-Lunstad, Smith, Baker, Harris, Stephenson, 2015). This places loneliness in the same category as smoking and obesity as a health risk. Forty years ago, obesity was identified as a health risk. Over the ensuing decades much public attention has been paid to this issue. In the last few years, more media attention has been paid to the issue of loneliness as a public health issue and have moved to develop public health campaigns to address loneliness (Campaign to End Loneliness, 2011) is another factor in the call to treat loneliness as a public health concern.

**Gaps in existing literature.** The existing research that examines the relationship between recovery setting and loneliness is limited. While much empirical evidence exists on the constructs of loneliness, social support, recovery settings, cardiac illness, and socio-demographics, there are few that compare loneliness between home and nursing home settings and none that use the Health Belief Model as a framework. This study will address gaps in the literature that address these issues and do so using a theoretical model and methodology that are unique.

Current research is lacking when assessing differences in loneliness between those in nursing homes and those at home for individuals with no cognitive impairment (Drageset, Kirkevold, & Espehaug, 2011; Pinquart & Sorensen, 2001Previous studies using subjects with cognitive impairment have often used proxy respondents (family members or professional care providers) to indicate that the older adult is or is not lonely (Missotten et al., 2009; Nikmat, Al-Mashoor, & Azreen, 2015; te Boekhorst et al., 2009). This study focuses on individuals who have no cognitive impairment (as measured by widely used and accepted assessment tools), which may improve the understanding of loneliness in home and nursing home settings as perceived by persons who are able to remember and reflect on their own experiences.

Studies that use both a direct and indirect measure of loneliness exist, but not in the context of comparison by setting. The Health Belief Model (HBM) has not been used in loneliness research to date, and yet the language of the HBM closely matches that of loneliness (expectation and perception) and has been used to show that changes in expectations and perceptions can lead to improved health behavior. The moderating influence of social support has strong evidence in the literature, and yet it is not clearly understood how social support might moderate loneliness between settings. Finally, the use of both qualitative and quantitative methods has a history in loneliness research. Using this methodology to make sense, not only of the difference in measured loneliness between nursing home and in-home settings, but adding the in-depth interviews with individual older adults currently in those settings, will help answer questions of why there might be a difference.

# **CHAPTER 3**

## METHODOLOGY

Michigan State University's Institutional Review Board determined the study was exempt on January 30, 2017 (qualitative data) and July 5, 2017 (secondary data analysis). Three additional Institutional Review Boards reviewed the study: Covenant Healthcare provided a full board review and approved the study; MidMichigan Regional Medical Center provided a partial review and approved the study; Saginaw Valley State University provided a partial review and approved the study (See Appendix 1 for all IRB documents). A fourth recruitment site was approved but did not produce any interviews.

# **Quantitative Data**

#### **Data Source - The Health and Retirement Study**

For this mixed method, exploratory study, the quantitative data came from the Health and Retirement Study (HRS), a longitudinal study of individuals and their households (Juster & Suzman, 1995). The HRS is sponsored by the National Institute on Aging (grant number NIA U01AG009740) and is conducted by the University of Michigan (Health and Retirement Study, 2014). Additional cohorts have been added since the initial iteration of the sample in 1992. The most recent addition came in 2010 with Middle Baby Boomers born between 1952 - 1958. This method has resulted in a nationally representative sample of the United States population over the age of 50 (Heeringa & Connor, 1995). As of 2016, twelve waves of data have been collected. Eleven waves of data (1992 – 2014) have been released for public use (with on-line registration) (Health and Retirement Study, 2008). The HRS includes data on both physical and cognitive health as well as health behaviors and health service utilization. This study uses pooled data from 2008 – 2014.

**Sample.** The HRS uses a mixed method approach to data collection. Every four years, all participants engage in both a face-to-face interview and telephone survey (Health and Retirement Study, 2008). Face-to-face interviews end with a leave-behind survey that includes a direct question about loneliness, an indirect measure of loneliness, and a perceived social support scale. From the complete sample of non-duplicate cases in the HRS study from 2008 – 2014 (n=38185), participants who answered the leave-behind survey were included if they were age 60 years and older, had a history of cardiac illness, and were cognitively intact (n=29940). Additionally, this cross-sectional data included only the first time a participant identified that they were in a nursing home, had used in home care in the previous two years, or had met neither of these conditions (home only). A complete list of variables used in the sample can be found in Appendix 2 (items in bold indicated inclusion criteria). These criteria resulted in the following (Figure 2) number of participants for each wave and total number of participants:





# **Dependent Variable**

**Loneliness**. Loneliness is the dependent variable for this study. It was measured using a three-item scale developed by Hughes, Waite, Hawkley, and Cacioppo (2004) specifically for

use in the HRS using items from the R-UCLA Loneliness scale (Russell et al., 1980). The three items are: How much of the time do you feel you lack companionship? How much of the time do you feel left out? And How much of the time do you feel isolated from others? Response options are 1=Often, 2=Some of the time, and 3=Hardly ever or never. An index of loneliness is created by reverse coding the three responses and averaging all scores so that a higher score indicates more loneliness. Reliability of the scale for this study is  $\alpha$ =.72 which is comparable to previous studies. Consistent with previous research, a participant was coded as lonely when they answered Often or Some of the time (Shaw et al., 2017). This dichotomous measure is used in subsequent analyses.

#### **Independent Variables**

**Recovery setting.** The HRS includes questions about where the participant is living at the time of the interview and leave behind questionnaire. These questions are used to identify participants as 1) living in a nursing home, 2) living at home with in-home care, or 3) living at home with no professional in-home care (referred to from here on as "home only"). Living in a nursing home includes participants who are currently living in a nursing home setting and have participated in the survey previously. Living at home with in-home care includes participants who indicate they have used professional care services in the past two years.

**Demographics.** Age is a continuous variable calculated from reported birth year. Gender is reported dichotomously as male or female. There is no option for other gender identity in the HRS. Ethnicity is measured as a yes/no question regarding identification as Hispanic or Latino. Race is reported using the following options: White/Caucasian, Black/African American, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, or Other (specified).

For the purposes of this study, race was collapsed into three variables: White/Caucasian, Black/African American, and Other.

Socioeconomic status (SES) is broadly defined as access to financial, social, cultural, and human capital resources (American Psychological Association, 2017; National Forum on Education Statistics, 2015), and is measured in multiple ways. For this study, education (highest level achieved), household income, and a measure of poverty (qualifying for food stamp/SNAP) were used to determine socioeconomic status. Highest level of education was collapsed into four variables: less than high school, high school, some college and associate or bachelor's degree, and graduate degree (PhD, MD, JD, etc.). Income is a continuous measure of household income that includes income of both the participant and spouse from work, social security, worker's compensation, and wealth income (rental property, retirement accounts, etc.). Receipt of welfare or food stamps/SNAP (Supplemental Nutrition Assistance Program (SNAP)) is indicated with a dichotomous variable coded 1 for yes and 0 for no.

An additional measure of socioeconomic status was a subjective measure of social status using a tool based on the Cantril Ladder (Cantril, 1965). The MacArthur Scale of Subjective Social Status was designed to use a similar ladder to measure perceived social status of participants, an additional aspect of socioeconomic status (Adler & Stewart, 2007; American Psychological Association, 2017). Participants are asked to mark an X on the ladder and are instructed to think of the ladder as representing where people stand in society. The ladder is described as, at the top, including people who are best off (most money, education, and jobs) and, at the bottom, those who are worst off (least money, education, and worst or no jobs). Reponses were divided into three groups: Low SSS (Subjective Social Status) (rungs 1-3),

Middle SSS (rungs 4-7) and High SSS (rungs 8-10). This is consistent with previous studies (Chen, Covinsky, Cenzer, Adler, & Williams, 2012).

**Social support.** The leave behind survey included measures of social support. Support is examined from spouse/partner, living children, other family members, and friends. For each source of support there are seven items - three positive items (perceived positive social support) and four negative items (perceived negative support) – for a total of eight social support scales that includes two for each source of support. Questions were developed using studies conducted by Cohen (2004) and Uchino (2009) and were tested for reliability in the 2006 – 2010 waves. Reliability for this study are between  $\alpha$ =.801 and  $\alpha$ =.822 for the positive items and between  $\alpha$ =.845 and  $\alpha$ =.869 for the negative items which are comparable to that found in previous studies (Health and Retirement Study, 2008).

For perceived Positive Social Support participants were asked: "How much do they really understand the way you feel about things?", "How much can you rely on them if you have a serious problem?", and "How much can you open up to them if you need to talk about your worries?". Perceived Negative Social Support questions were: "How often do they make too many demands on you?", "How much do they criticize you?", "How much do they let you down when you are counting on them?", and "How much do they get on your nerves?". Response options were 1=A lot, 2=Some, 3=A little, and 4=Not at all. All items are reverse coded. Indices are created by taking the mean of the items, with higher scores indicating more positive or negative social support respectively.

#### **Missing Data**

Participants with missing data on all variables were identified. For missing data on the loneliness and social support measures, previous literature (Hawkley & Cacioppo, 2010; Cohen,

2004; Uchino, 2009) instructed that the final score should be set to missing if there is more than one item with missing values for the three item scales and more than two items missing for the four item scales. Additional analyses were conducted to identify patterns in missing data that might bias results. Those with missing data on the six social support scale variables were more likely to be non-Hispanic, White/Caucasian, with a High School Diploma or GED, and widowed. For the Spousal Support question (both positive and negative), it would make sense that persons who were Widowed, Divorced, or Never Married would not answer the spouse questions. Based on analysis of the question "Do you have" Children, Other Family, or Friends, this is true for these other questions as well.

#### **Analytic Strategies**

Bivariate comparisons by setting – nursing home, at home with in-home care, or home only – were conducted for all study variables using chi-square tests for categorical variables and ANOVA for continuous variables. Multivariate analyses were conducted on the dichotomous measure of loneliness using logistic regression. The model was first run including setting – the main variable of interest – controlling for demographic variables. Then social support was included with each source of support being included separately for a total of six models. Finally, interaction terms between setting and each of the social support variables were included individually to examine whether social support moderates the relationship between setting and loneliness. Analyses were conducted in SPSS v.24.

#### **Qualitative Data**

This study used Interpretative Phenomenological Analysis (IPA), a method of inquiry used to make sense of life experiences. IPA was chosen, over other qualitative approaches such as grounded theory and phenomenology, because of the focus on interpretation of meaning from

experience. The method has also been used in health psychology which matched the focus of the study, loneliness in the context of health behavior. Finally, Interpretative Phenomenological Analysis employs a key characteristic for the approach that recognizes the influence of the researcher's own biographical background and knowledge. The researcher interprets the data through their own lens of experience when developing themes (Smith, 2004).

IPA in this study employs semi-structured interviews to understand the lived experiences, particularly the experience of loneliness, of older adults recovering after hospitalization. Sampling is purposive and focuses on a small number of participants (Smith & Osborn, 2003). Interpretive Phenomenological Analysis, although providing a guideline, does not specify the number of individuals required to complete an understanding of a phenomenon. Smith, Flowers, and Larkin (2013) suggest between three and six participants for a given study. The authors note that this number provides for sufficient information to develop meaningful differences and similarities between cases (Smith, Flower, & Larkin, 2013). For this study, that was interpreted to mean under 10 interviewees for each recovery setting – nursing home or at home with inhome care. Fourteen semi-structured interviews were conducted with a purposive sample of older adults in the Great Lakes Bay Region. This geographic location was convenient and offered the possibility of a diverse population from which to gain a sample of participants who met the inclusion criteria.

#### Study sample

The sample inclusion criteria consisted of individuals who: were age 60 years and older, were discharged from the hospital, had a diagnosed heart condition, were recovering in a nursing home or in the home, and were cognitively intact. Cognitive status was determined at two points through use of validated measures of cognitive function. For pre-screening of potential

interviewees in the hospital and nursing home settings either the Mini-Mental Status Exam (MMSE) or the Brief Interview for Mental Status (BIMS) were used. The Montreal Cognitive Assessment (MoCA) was administered to each interviewee prior to the start of the interviews. Exclusion criteria included individuals whose primary language was not English and those who were receiving or who were being discharged with hospice services. These criteria resulted in eight interviewees from the in-home setting and six interviewees from the nursing home setting. Enrollment was concluded for a combination of reasons including reaching the target number (in-home), time constraints (nursing home), and reaching saturation of information (both settings).

#### **Study Sites and Method of Recruitment**

Three methods of recruitment were used to obtain the sample. At study Sites One and Two, employee researchers were trained on the goals of the study and how to approach potential interviewees. Internal medical records were used to identify individuals who met inclusion criteria including age, cardiac diagnosis, and without cognitive impairment. Cognitive status was determined using the BIMS (Brief Interview for Mental Status) and MMSE (Mini-Mental Status Exam). Exclusion criteria at both sites included individuals who were not assessed as cognitively intact and those who were discharged with hospice.

In Site One, the employee researcher met with eligible interviewees and provided a brief description of the study as introduction (See Appendix 3). If the patient was interested, the employee researcher read the entire Informed Consent agreement (See Appendix 4) and had the patient sign the agreement. The patient was given a copy of the informed consent. The employee researcher then contacted the secondary researcher to tell them that they had a name. The secondary researcher drove to Site One and obtained the name.

In Site Two, a flyer was placed in the discharge paperwork of eligible interviewees. The potential interviewee was reminded of these materials during a follow up phone call by the employee researcher. A script was provided to both the discharge staff and the employee researcher to address any potential questions patients had about the study (See Appendix 3). Patients then contacted the secondary researcher using the flyer information. Addresses were obtained during these phone calls.

In both sites 1 and 2, following the provision of an address for the interviewees, the secondary researcher sent an initial assessment through postal mail. An on-line version of the assessment was available; however, no interviewees chose to use the on-line method. The assessment included validated measures of loneliness and social support. Loneliness was measured using the De Jong Gierveld Loneliness Scale - Short Version. This multidimensional scale measures both the emotional and social aspects of loneliness (Nicolaisen & Thorsen, 2014). The six-item scale was used to limit response burden for a population that has limited time or energy. The scale authors note no difference in reliability and construct validity between the long- or short-versions of the scale nor whether used in a self-administered questionnaire or in face-to-face interviews (De Jong Gierveld & Van Tilburg, 2006). A Cronbach's alpha of  $\alpha = .86$ has been observed in psychometric testing of the scale (De Jong Gierveld & Kamphuis, 1985). Please see Appendix 5 for the complete instrument along with detail on psychometrics, coding, and scale development. Comparisons of the Three-Item Loneliness Scale used in the HRS (Hughes, Waite, Hawkley, & Cacioppo, 2004) and the DeJong-Gierveld Loneliness Scale (De Jong Gierveld & Van Tilburg, 2006) are few, however, there are noted similarities and differences. The main difference is that the Three-Item Loneliness Scale is unidimensional, while the De Jong Gierveld scale is multidimensional, capturing both emotional and social loneliness.

The emotional loneliness sub-scale of the DeJong-Gierveld instrument is most closely associated with the Three-Item Loneliness Scale (Shiovitz-Ezra & Ayalon, 2012).

The DeJong-Gierveld instrument is a six-item scale and includes the following questions: 1) I experience a general sense of emptiness, 2) I miss having people around me, 3) I often feel rejected, 4) There are plenty of people I can rely on when I have problems, 5) There are many people I can trust completely, 6) There are enough people I feel close to. Response categories are Yes / More or less / No. The scale is scored by identifying neutral and positive answers on the negatively worded items (emotional loneliness) as having a score of "1." The positively worded items (social loneliness) are scored by giving neutral and negatively worded items a score of "1." Thus, when scores are totaled, an emotional loneliness score is calculated from 0 (not emotionally lonely) to 3 (intensely emotionally lonely) and a social loneliness score also from 0 (not socially lonely) to 3 (intensely socially lonely). Scores for each question can be combined for an overall, unidimensional score ranging from 0 (least lonely) to 6 (most lonely).

Social support was measured using the Lubben Social Network Scale (LSNS). The LSNS is a six-item measure of perceived social engagement including family and friends. The scale was tested on older adults and has good reliability with a Cronbach's alpha of  $\alpha = 0.83$  (Lubben et al., 2006). The scale includes three questions relating to family relationships and three questions relating to friend relationships. Interviewees indicate the number of individuals who meet each criterion. Specifically, interviewees are asked: "How many relatives/friends do you see or hear from at least once a month?", "How many relatives/friends do you feel at ease with that you can talk about private matters?", and "How many relatives/friends do you feel close to such that you could call on them for help?" Response options include: 0=none, 1=one, 2=two, 3=three or four, 4=five thru eight, 5=nine or more. The six-item measure includes scores ranging

from 0 to 30. Higher scores indicate more engagement. A sample of the LSNS can be found in Appendix 5. While there are no studies comparing the Perceived Social Support measure used in the HRS and the Lubben Social Network Scale, both are considered measures of perceived social support (Baigi, Hildingh, Virdall, & Fridlund, 2008; Lubben & Gironda, 2004).

Interviewees were offered two incentives: one for completing the assessment (a drawing for a \$100 Visa gift card) and one for participating in a face-to-face interview (\$25). Return envelopes with postage were included with all mailed assessments (please see Appendix 5 for copies of the assessment). Twelve names were provided to the secondary researcher from Sites One and Two. Of these, eight returned the assessment, agreed to participate in the drawing, and agreed to participate in the interview. Additional enrollment numbers are noted in Table 1 below:

Table 1										
Summary of enrollment sites										
	Consent	Flyers	Assessments	Assessments	Interviews					
Organization	requested	given	sent	returned	completed					
Site One	23	na	8	5	4					
Site Two	na	29	4	4	4					

Additional recruitment was undertaken, once it was determined that sites 1 and 2 were only going to provide interviewees who were recovering at home. Twenty-one nursing homes in the Great Lakes Bay Region were sent a letter on June 26, 2017. The letter detailed the study and a flyer with information on the study and contact information for the researcher was enclosed with the letter (See Appendix 6). Follow up phone calls were made to all twenty-one nursing homes on July 7, 2017. Of the twenty-one nursing homes contacted, two expressed interest in participating in the study. Six nursing home residents agreed to participate in the study, four from Nursing Home One and two from Nursing Home Two. The secondary researcher spoke with each of them directly to obtain their name and room number. The nursing home address was already known to the secondary researcher. The interview began with the assessment noted above (See Appendix 5) and the interviewees were offered the opportunity to enter the drawing for \$100.

All interviewees were interviewed in a setting in which they were comfortable and were offered the opportunity to have anyone with them if they desired. All interviewees agreed to audio recording of their interview. All interviewees received a \$25 Visa gift card. The gift card was provided at the beginning of the interview as stipulated in the IRB applications. This ensured that, even if the interviewee did not meet the cognitive assessment requirements and/or chose to end the interview prematurely, they kept the incentive. None of the interviewees failed the cognitive assessment and none chose to end the interview, nor, at the time of this writing, have any interviewees contacted the secondary researcher to have their data removed from the study. Please see Appendix 7 for all interview materials.

**Characteristics of settings.** Interpretive Phenomenological Analysis emphasizes the environment in which the experience being analyzed takes place. Interviews were conducted in both the nursing home (n=6) and in-home (n=8) settings.

*Nursing home*. Four interviews were conducted in Nursing Home One. Nursing Home One is privately owned and is in the Great Lakes Bay Region. The facility has multiple wings and none are designated specifically for a certain type of recovery. The facility accepts Medicare, Medicaid, various insurances, and private pay. Nursing Home One uses an interdisciplinary staff of professionals and includes in-house physical therapy services for rehabilitation.

Three interviews in Nursing Home One were conducted in the residents' semi-private room. The residents' roommates were not present. During one interview, the television was on throughout the interview and the interview was conducted with the resident sitting in a

wheelchair next to the bedside. For the other two in-room interviews, the television was off and the interviews were conducted with the resident in bed, partially sitting up. The fourth interview was conducted in a common room at the front of the building at the resident's request. No one was present in the room during the interview. Residents, staff, and visitors passed by the common room during the interview, however no one came into the room.

Nursing Home Two, where two interviews were conducted, is a corporate owned facility specializing in cardiac rehabilitation. Average length of stay for the rehabilitation unit is fourteen days. The facility is modern and well-maintained. An interdisciplinary staff of caregivers provides comprehensive services. Most rooms in the rehabilitation unit are single occupant. The two interviews were conducted in residents' rooms. The first interview, in a single-occupancy room, was interrupted during the cognitive assessment. The interview was resumed the next day and the cognitive assessment was completed. The TV was on and muted and there were no additional staff or visitors in the room at the time of the interview. The second interview was completed in the resident's semi-private room. No one else was in attendance and the television was not on.

*In home*. Seven of the eight home interviews were conducted in the interviewee's own home. One interview was conducted in a restaurant at the interviewee's request. Of the seven interviews conducted in the interviewees' homes, four were conducted with no one present but the interviewee, while three were conducted with one additional individual present at the interviewees' request. All seven were conducted in the Great Lakes Bay Region. Each home was single occupancy and well maintained. The eighth interview was conducted in a restaurant in the Great Lakes Bay Region. The interviewee brought a family member to the interview and the

interview was conducted in a private area of the restaurant. A description of the interviewee's primary home was given during the interview.

## **Interview Protocol**

Following introductions and verbal consent to audio record the interview, one of two procedures was used for the interview. If the interviewee referral came from Site One, the informed consent document and the individual's signature were reviewed prior to the start of the interview. The interviewee's willingness to engage in the interview was confirmed. If the interviewee came from either Site Two or from the nursing home outreach, the interview commenced with a review of the consent form. The interviewee's signature was required on the form to start the interview. A copy of the consent was provided to the interviewee and the signature page was retained by the secondary researcher.

Once consent was confirmed or obtained, the interview proceeded. For those who had not completed the assessment previously, the assessment was completed, and the interviewees were asked if they wanted to enter the drawing. Their names and addresses were then recorded on the assessment form. For those who had completed the assessment previously, the form was reviewed with them and their agreement to enter the drawing or not was confirmed. All interviews then proceeded using the same protocol.

Each interviewee was asked to complete a cognitive assessment. The Montreal Cognitive Assessment (MoCA) versions 7.1, 7.2, and 7.3 were used. Interviewees all obtained scores that indicated that they were not cognitively impaired, and the interview progressed. The interviews were open-ended and semi-structured and lasted from 40 to 70 minutes. There were six questions covering four topic areas: hospital discharge, expectations of social support, current perceptions of social support, and difference between expectations and perception. Each question included

multiple probes, which were often employed in the interviews. At the end of the interview, interviewees were given detailed information on the study purpose and potential outcomes.

The first topic of the interview, hospital discharge, included questions that asked the interviewee to recall their hospital stay, why they were in the hospital, what their discharge experience was like, and their level of participation in discharge planning. The second topic asked interviewees to think about the term "social support" and to identify if they had any expectations about social support following their discharge. Initially, the interviewee was given leeway to self-define social support. Probes provided more detail about the meaning of social support, expectations, and possible scenarios if expectations were discussed prior to discharge. The third topic asked the interviewee to assess their current perception of social support would be helpful in their recovery. Finally, interviewees were asked to consider the difference between their expectations of social support at discharge and their current perception of social support in their recovery setting. Interviewees were asked about their feelings about possible differences to explore this experience more thoroughly.

The last question asked was one that allowed the interviewee to expand on any additional information they thought was relevant. Interviewees were encouraged to talk about anything that they felt about discharge, recovery, expectations, and perceptions. The goal of this section of the interview was to gain any further insight into the interviewee's understanding of their experience and what it meant to them. Finally, the secondary researcher provided the literature definition of loneliness and then asked each interviewee: Do you feel lonely? Once all comments were completed, the secondary researcher provided the interviewee with information on the goal of the study and asked if the interviewee would like a copy of the final report.

The semi-structured nature of the interview allowed the secondary researcher to change the order of the questions as was warranted in each interview. It was the secondary researcher's goal to ensure all questions were asked in each interview. The addition of the "Do you feel lonely?" question at the end of the interview came about in response to the first interviewee's inquiry as to the nature of the research. The direct question, coming at the end of the interview, did not skew the indirect nature of the earlier questions and provided interesting insight into the thoughts and feelings of each interviewee. In addition, the use of both indirect and direct measures of loneliness in the interview mirrors the indirect and direct questions included in the quantitative portion of the study.

At the conclusion of the interview, all interviewees were reminded of the gift card they had been provided, if they had agreed to the drawing their address was confirmed, and all were assured of the inclusion of contact information for each relevant IRB and the researcher. If the interviewee requested a copy of the report after the study, that information was also confirmed. Interviewees were reminded that they could contact the researcher or the IRB at any time if they decided later that they did not want their answers included in the study.

## **Data Analysis**

All interviews were conducted, audio-recorded, and transcribed by the secondary researcher. Audio recordings of five of the interviews were sent for confirmatory transcription to a licensed transcriptionist. No identifying information was included in the audio-recording, thus ensuring confidentiality as required by the Covenant Healthcare IRB. The transcribed audio-recordings comprised 232 single-spaced pages across all 14 interviews.

The secondary researcher maintained a log of all interview interactions (See Appendix 8 for a sample from the field log). In addition, a spreadsheet with the location of all notes of

interactions with interviewees was maintained throughout the study. The independent audit trail is available with locations of all data, reviews of transcripts, coding schemes, interpretations, and findings summaries. This is one method used to increase the trustworthiness of the data. Upon completion of confirmatory comparisons between transcribed audio recordings, all data was imported into qualitative data analysis software (NVivo) for additional coding and analysis.

## **Interpretive Phenomenological Analysis**

Interpretive Phenomenological Analysis (IPA) was developed in the tradition of psychological research (Smith, Flowers, & Larkin, 2013) and using many of the principles of phenomenology laid out by Moustakas (1994). The emphasis of the approach on lived experience, considering both the psychological state of the individual, as well as the environmental context of the experience, speaks well to the person in environment approach of social work. IPA is grounded in hermeneutics, the theory of interpretation, and encourages an empathic understanding of the individual being interviewed as well as interpretation of the experience through the lens of other theoretical models (Smith, Flowers, & Larkin, 2013). A double hermeneutic process is used, with the process of the researcher making meaning of the interviewee who is making meaning of their own lived experience. Using IPA for this study allows for the person (older adult) to be understood in their recovery setting (environment) through the lens of the Health Belief Model, which may help to explain the experience of loneliness.

Interpretive Phenomenological Analysis suggests a cyclical approach. This results in a continual examination of the whole experience (discharge and recovery following a hospital stay) through the parts that make up experiences (where the recovery takes place, expectations and perceptions of social support, experience of loneliness), as well as examination of the parts

that make up the whole. The researcher begins with an acknowledgement of their own preconceptions of the experience being examined. In this study, the secondary researcher began, prior to engaging in any interviews, with a reflection and examination of her own beliefs and understanding of loneliness, recovery setting, and social support (See Appendix 9 for the Interviewer Reflection). Using a twenty-five-year career in various areas of older adult service and long-term care, the secondary researcher examined her own ideas of why discharge of older adults from hospital is a rushed experience with little attention paid to the desires of the patient and more emphasis placed on, in order: expedience, cost, and family input. The professional home care experience of the secondary researcher, and the experience both as a nursing home social worker and long-term care ombudsman, brought ideas about loneliness and the need for understanding of the concept beyond the number of people with whom the older adult engaged. This combination of social support and loneliness as keys to the secondary researcher's preconceived notions of experiences of older adults recovering from illness were analyzed through reflective journaling prior to commencement of study interviews. It was through this process that the secondary researcher could bracket the information; a concept described in IPA as acknowledging and then setting aside these preconceptions (and doing so throughout the analysis) to attend to the experience through the eyes of the interviewee (Smith, 2004). This bracketing was done both at the start of the study and at various points during the different interviews in an attempt to understand interviewer bias.

IPA focuses on human lived experience (Callary, Rathwell, & Young, 2015; Clare, Rowlands, Bruce, Surr, & Downs, 2008). In the context of this study, this would emphasize that the examination of the perception of loneliness be discussed in the recovery setting. This situates the interviewee in their specific context, either nursing home or in home. IPA describes this lived

experience as one where an event that may seem to some as ordinary, becomes extraordinary as the individual reflects on the experience and tries to make sense of it (Smith, Flowers, & Larkin, 2013).

## Coding

Qualitative data analysis followed steps outlined in IPA (Smith, Flowers, & Larkin, 2013). The transcripts were read and re-read, both with and without accompaniment of the audio recording; this is identified as the first step in the IPA analysis process. This iterative process allowed for an analysis that went back and forth between researcher interpretation and interviewee understanding. This process also allowed for interpretation based on non-verbal tone of voice, pauses, laughter, and inflection. This second step of IPA is called initial noting and included descriptive and conceptual comments. The line by line review of each transcript with notation of the word choice used and the context in which the statement was made (consideration of the question, length of time it took to answer, pauses, etc.) was completed for all interviews. Themes emerged from this second step which were coded and noted in the transcripts chronologically (as they came up) on the hard copies of the transcripts (step three). Language use, including the use of metaphor and word choice, was examined within each transcript, and was noted. While the use of technology to assist in this process is new to Interpretative Phenomenological Analysis, it is acceptable when technology is the normal practice for the researcher. Thus, for this study, NVivo qualitative software was used to help code each individual transcript. Nodes (NVivo terminology for codes) were identified for each transcript, some of which corresponded with the hand-written codes and others that emerged during the computer aided analysis of the data. Step four included noting the discrepancies and linearity from the hand-noted codes and identifying them in the NVivo software

Step five dictates that the first four IPA steps be conducted for each individual case.

Word choice is analyzed and meaning from specific words and phrases used are included in the analysis. In step 6 the data are examined for patterns across all cases. The use of metaphor and language choice is examined for thematic inclusion across all cases. The previous steps have led to interpretation from the individual to the whole and is mostly descriptive in nature. The review of the entire data set allows for deeper interpretation from the whole back to the individual cases. This back and forth (iterative) process provides for a close reading of the interviewee's perception of events and the researcher's interpretation of that perception in the context of other interviewee's perception (Smith, Flowers, & Larkin, 2013).

## **Rigor of Qualitative Data**

Interpretative Phenomenological Analysis (IPA) recognizes two methods of assessing the quality of the qualitative data gathered. Padgett (2008) defines rigor in qualitative methodology as vigilance in attention to methods and the self-discipline needed to separate the researcher from the interviewee. Padgett (2008) goes on to include trustworthiness as part of the definition of rigor; citing the idea that a study that is trustworthy is one that is fair and ethical with findings that are representative of experience and meaning of the interviewees. Yardley (2000, 2017) uses four principles for quality assessment: sensitivity to context, commitment and rigor, transparency and coherence, and importance. IPA identifies an independent audit as an appropriate measure of validity of a qualitative study. For the purposes of this study, the principles of the independent audit were followed, specifically the detailed description of the trail of data. It was determined, given the requirements of the IRB and the necessity of confidentiality, that having another researcher review this data trail was not appropriate. Thus, quality is assured through

adherence to the tenets of audit and, more specifically, by attending to Padgett's (2008) ideas of rigor and trustworthiness and the principles laid out by Yardley (2000, 2017).

The study addresses vigilance in all aspects of interviewee enrollment and data collection and analysis. This attention is demonstrated in the ability of readers to follow all steps taken in the research project and to replicate the study with little to no additional inquiry required. Selfdiscipline was used by attending to bracketing as laid out in Moustakas (1994) and Smith, Flowers, and Larkin (2013). The trustworthiness of the study is confirmed by the specific attention paid to IRB approval and the secondary researchers continuous efforts to ensure, through contact with the IRBs involved, that the rights of all interviewees was maintained. These methods are part of the strategy Padgett (2008) describes as important to address the quality of the qualitative data.

The study attends to the principles for quality laid out by Yardley (2000, 2017). The first principle, sensitivity to context, was addressed using the tenets of IPA as laid out by Smith, Flowers, and Larkin (2013). From the inception of the qualitative portion of the study, the secondary researcher has used the theoretical foundation of IPA, with attention paid to question development, interview protocol, and data analysis. This sensitivity to the context of this particular form of phenomenological research addresses Yardley's (2017) first principle. By recognizing the need to purposively seek out participants and meet them in their own environment, IPA addresses some of the socio-cultural issues Yardley (2000, 2017) identifies as an important part of the assessment of quality. This study, as is typical of many IPA studies, targeted individuals with common experience who were not particularly easy to reach. The effort needed to seek out and enroll these individuals in the study speaks to the need to ask particular questions and understand the participant's meaning making of their recovery setting in

their own environment and not in one created or convenient for the researcher. This sensitivity continues through the analysis of the data with the researcher setting aside, or bracketing, their own understanding, in an effort to make sense of the meaning described by the participant.

Yardley's (2017) second principle, that of commitment and rigor, aims to address the thoroughness and dedication of the researcher in attending to the participant and the data collected. For this study, the secondary researcher attended to the needs of the participant by engaging in the interview at the participant's convenience and in a place that made the participant as relaxed and comfortable as possible. The secondary researcher conducted the interviews in a semi-structured format which was adaptable as the secondary researcher reflected on ways to improve the method of questioning and attended to the need to improve interview skills following each interview. As to thoroughness, the principles of IPA guided the sample size for the study, however these were guidelines that were sensitive to the data collected over time and allowed for a complete understanding of the health behavior loneliness in both the home and nursing home settings. Analysis of the gathered data also attends to commitment and rigor by using the principles of IPA throughout data analysis. These principles guide a thorough understanding of the individual participant in their specific context, the grouping of the experience of participants in either the in home or nursing home setting, and a more global understanding of the experience and meaning of loneliness broadly across settings at both the group and individual levels. This movement of attention to detail at and between the micro (individual), mezzo (groups), and macro (larger picture) levels, provides for a more thorough understanding of the meaning.

The third area described by Yardley (2000, 2017) and endorsed by Smith, Flowers, and Larkin (2013) for use with Interpretative Phenomenological Analysis (IPA) is transparency and

coherence. The stages of this research study are described in depth in this document. From the literature search which grounds the study in previous understanding and theory, to the method used for the qualitative research with detail of sample and interview, to the process of data analysis and conclusion, each step is described in detail and with attention paid to the tenants of the IPA process. The writing has gone through multiple drafts with attention paid to the coherency of argument and theme as well as potential contradictions and ambiguity. The attention paid to the theoretical basis of IPA and the need to attend to the theory of interpretation, the iterative nature of the data analysis, and the inductive movement of specific observation to broad conclusion, combine to address the coherence and transparency of the project.

Finally, Yardley (2000, 2017) describes quality qualitative research as having both impact and importance. This is a standard for which this study strives. It is not possible to surmise that the results of the study, the conclusions drawn by this researcher from the analyzed data, will have impact or importance. The addition of the study to the broader conversation of peer reviewed literature will be judged by those that read this report, and possibly by those who use this information to inform future understanding of the issue of loneliness in the context of recovery.

#### **Combining the Qualitative and Quantitative Analysis**

A final step in the data analysis included an iterative analysis of both the quantitative and qualitative data. By framing the analysis in terms of the three research questions, the themes identified in the qualitative analysis were compared with the results of the secondary data analysis to give broader meaning. The exploratory nature of the research, considering the dearth of information on the topic of loneliness comparing similar populations in nursing home and home care, allowed for meaning to be attributed from the perspective of the qualitative

interviews enhanced with the quantitative data. Additional insight, gained from the secondary researcher's reflections on the environmental context and the secondary researcher's own prior experience, a specific characteristic of Interpretative Phenomenological Analysis, completed the method used in this study.

#### **CHAPTER 4**

# RESULTS

The results of this study are presented in two sections – quantitative and qualitative results - with a summary of findings at the conclusion of this chapter. Data analysis was an iterative process, moving between the quantitative secondary data and the qualitative interviews. Information from interviews, conducted at the same time as the secondary data analysis, was used to identify additional comparisons of the secondary data set. As an example, the decision to run linear regression on each individual area of social support available in the data (Spouse, Family, Other Family, and Friends) rather than the combined social support of all four areas, was informed by the qualitative interviews where interviewees identified differences in support from family and friends.

## Quantitative data

Table 2 shows demographic characteristics of older adults in the sample, presented separately for each of three settings, nursing home, at home with previous home care, and home only. Just under half of the sample is female (48.45%) while the majority are white (85.2%) and non-Hispanic (94%). Most participants are married (64.4%) and 23% are widowed. More than half of all participants had a High School Diploma or GED (54.6%). Only 6.7% of all sample participants indicated that they were eligible for Food Stamps/SNAP. Most participants rated themselves as middle (54.9%) or high social status (28.6%) although the average income was \$29,703 (SD=\$64,988). The average age of the full sample was 75.81 (SD=7.51).

There are significant differences by recovery setting for gender, race, marital status, eligibility for food stamps/SNAP, age, and income. Overall, there were more men (51.6%) than women (48.4%) in the sample. However, a higher proportion of those living in a nursing home

(59.7%) or receiving care at home (51.9%) were women, while more of those in the home only group were male (52.7%). Race disparities were present by setting as well with a greater proportion of those in the home with previous home care (14.4%) or home only (10.5%) groups being Black/African American compared to those in a nursing home (8.3%). A higher proportion of those in a nursing home were widowed (55.6%) than in either of the other two settings (27.6% and 21.4%) while more of those at home with care (59.9%) or home alone (66.4%) were married compared to those in a nursing home (26.4%). A higher proportion of those at home with previous home care were eligible for food stamps/SNAP (11.1%) than in either a nursing home (2.8%) or home only (5.8%). Those living in a nursing home were older (M=82.9) compared to those receiving previous home care (M=77.7) or living at home only (M=75.2). Mean income for those at home (M=21132) and at home with previous home care (M=23126).

lable 2											
Description of key study variables	s (n=3,798)	)									
	Home with										
	Previous Home										
Variables	Total		Nursing Home		Care		Home Only		$\chi^2$	р	
	n	%	n	%	n	%	n	%		-	
Gender									8.85	.012	
Male	1960	51.6	29	40.3	346	48.1	1585	52.7			
Female	1838	48.4	43	59.7	374	51.9	1421	47.3			
Race									10.08	.039	
White/Caucasian	3234	85.2	63	87.5	592	82.2	2579	85.8			
Black/African American	426	11.2	6	8.3	104	14.4	316	10.5			
Other	127	3.3	3	4.2	21	2.9	103	3.4			
Ethnicity									1.43	.490	
Hispanic	218	5.7	2	2.8	39	5.4	177	5.9			
Non-Hispanic	3570	94.0	70	97.2	678	94.2	2822	93.9			
Marital Status									65.97	<.001	
Married	2445	64.4	19	26.4	431	59.9	1995	66.4			
Divorced	343	9.0	8	11.1	62	8.6	273	9.1			
Widowed	882	23.2	40	55.6	199	27.6	643	21.4			
Never Married	77	2.0	3	4.2	14	1.9	60	2.0			
Education									11.821	.066	
Less than high school	820	21.6	14	19.4	185	25.7	621	20.7			
GED/High School Diploma	2072	54.6	45	62.5	370	51.4	1657	55.1			
Some College, Associates,	560	14.7	9	12.5	107	14.9	444	14.8			
or Bachelor Degree											
Graduate degree	346	9.1	4	5.6	58	8.1	284	9.4			
Table 2 continues on the next page	ge										

# Table 2
# Table 2 (cont'd)

# Description of key study variables (n=3,798)

					Home	with				
					Previous	s Home				
Variables	Tot	tal	Nursing	Home	Ca	re	Home	Only	$\chi^2$	р
Socioeconomic Ladder									2.73	.605
Low Subjective Social Status	224	5.9	5	6.9	50	6.9	169	5.6		
(SSS) (1-3)										
Middle SSS (4-7)	2062	54.9	35	48.6	376	52.2	1651	54.9		
High SSS (8-10)	1085	28.6	20	27.8	204	28.3	861	28.6		
Eligible for Food Stamps/SNAP									26.81	<.001
Eligible	256	6.7	2	2.8	80	11.1	174	5.8		
Not Eligible	2585	68.1	68	94.4	474	65.8	2043	68.0		
					Home	with				
					Previous	s Home				
	Tot	tal	Nursing	home	Ca	re	Home	Only	F	р
	М	SD	М	SD	М	SD	М	SD		
Age	75.81	7.507	82.9 <sup>a</sup>	7.57	77.74 <sup>a</sup>	7.60	75.18 <sup>a</sup>	7.32	68.98	<.001
Income <sup>b</sup>	29703	64988	23312	37818	23126 <sup>c</sup>	26104	31606 <sup>c</sup>	72028	3.82	.022
<sup>a</sup> Post hoc comparisons using Tuke	y's HSD s	show sign	ificant dif	fferences	in age acr	oss all thr	ee groups.			

<sup>b</sup>Reported in whole dollars

<sup>c</sup>Post hoc comparisons using Tukey's HSD show a significant difference between those at home with care and those at home only.

There are significant differences across setting for loneliness (Table 3) and social support (Table 4). A higher proportion of nursing home participants report being lonely (76.4%) compared to those living at home with previous home care (64.9%) and those in the home only category (58.2%).

Table 3										
Description of lo	onelines	s by setti	ing							
					Home	with				
			Nurs	sing	Previo	ous				
_	Tot	al	Ho	me	Home	Care	Home	Only	$\chi^2$	р
	n	%	n	%	n	%	n	%		
Dichotomous									21.09	<.001
Loneliness										
Measure										
Lonely	2271	59.8	55	76.4	467	64.9	1749	58.2		
Not Lonely	1502	39.5	16	22.2	245	34.0	1241	41.3		
Note: The test st	atistic u	sed is ch	ii-squai	e						

Positive spousal support (Table 5) is significantly lower among those living in a nursing home (M=8.25) compared to those with previous home care (M=10.32) or those in the home only group (M=10.40). Negative support from other family is significantly higher among those at home with care (M=6.19) compared to those at home only (M=5.94) and positive support from friends was significantly different across all three settings with the highest among those at home with support (M=9.13) followed by those at home only (M=8.92) and the lowest among those in a nursing home (M=8.05).

Table 4										
ANOVA and Post Hoc tests of socia	l support b	y setting	g							
					Home v	with				
					Previous	Home				
Variables	Tot	al	Nursing	Home	Care	e	Home (	Only	F	р
	М	SD	М	SD	М	SD	М	SD		
Perceived Spousal Support										
Positive	10.38	2.03	8.25 <sup>a,b</sup>	3.11	10.32 <sup>b</sup>	2.07	10.40 <sup>b</sup>	2.01	6.89	.001
Negative	7.69	2.70	8.64	3.30	7.72	2.77	7.68	2.68	.705	.494
Perceived Child Support										
Positive	9.82	2.20	9.95	2.31	9.92	2.18	9.79	2.20	.994	.370
Negative	6.61	2.58	6.62	2.88	6.79	2.70	6.57	2.55	1.94	.143
Perceived Other Family Support										
Positive	8.56	2.67	8.23	2.99	8.61	2.78	8.56	2.64	.567	.567
Negative	5.98	2.37	5.64	2.19	6.19 <sup>c</sup>	2.51	5.94 <sup>c</sup>	2.34	3.65	.026
Perceived Friend Support										
Positive	8.94	2.30	$8.05^{a,b}$	2.70	9.13 <sup>a</sup>	2.24	8.92 <sup>b</sup>	2.30	6.62	.001
Negative	5.53	1.94	5.66	2.31	5.56	2.06	5.52	1.90	.254	.776
Post hoc comparisons are made usin	ng Tukey's	HSD.								
<sup>a</sup> Nursing home is significantly diffe	rent from a	t home	with care.							
<sup>b</sup> Nursing home is significantly diffe	erent from h	ome on	ly.							
<sup>c</sup> At home with care significantly dif	ferent from	home	only.							

Results from the logistic regression are shown in Table 5. In Model 1, those in a nursing home are over two times more likely to report feeling lonely (Odds Ratio (OR)=2.44) while those at home with care are almost 1.5 times more likely to report feeling lonely (OR=1.35) compared to those living at home without care. When demographics are added in Model 2, setting is no longer significant indicating the relationship between settings and loneliness is related to other factors, not setting alone. Women have a significantly higher chance of being lonely (OR=1.21) compared to men. Those who are Hispanic are more likely to be lonely (OR=1.61) than are those who are not Hispanic. Marital status was significantly related to loneliness with persons who were widowed (OR=2.20), never married (OR=1.92), or divorced (OR=1.54) being more likely to be lonely compared to those who are currently married. Finally, individuals who identify themselves as middle (OR=.613) or high (OR=.396) social status were less likely to be lonely than those in the low SES group.

The effect of social support on loneliness when controlling for setting and demographic characteristics has some statistically significant results for all models. Positive social support from spouse (OR=.74), children (OR=.88), other family (OR=.91), and friends (OR=.90) all significantly reduced the likelihood that an individual would be lonely while negative social support from spouse (MD=1.23), children (MD=1.18), other family (MD=1.22), and friends (MD=1.23) significantly increased the likelihood that an individual would report being lonely.

Table 5												
Regression Models												
	Mod	el 1	Mod	el 2	Mod	el 3	Mod	el 4	Moo	lel 5	Mo	del 6
R-squared	.00	8	30.	35	.24	8	.15	57	.14	46	.1	40
-	OR	Р	OR	р	OR	р	OR	р	OR	р	OR	р
Setting				1		1		1		1		1
Nursing home	2.44	.002	1.28	.507	.23	.239	1.41	.404	1.27	.556	.95	.904
At home with previous	1.35	.001	1.16	.232	1.18	.382	1.16	.253	1.09	.520	1.31	.037
home care												
Demographics												
Women			1.21	.048	.98	.898	1.29	.015	1.23	.050	1.27	.021
Hispanic			1.61	.024	2.22	.011	1.67	.022	1.41	.130	1.65	.029
Race												
Black/African			1.34	.087	.92	.770	1.25	.230	1.22	.274	1.22	.287
American												
Other			1.24	.428	1.29	.506	1.08	.790	1.17	.607	1.36	.304
Education												
High School/GED			.90	.398	.91	.616	.89	.401	.88	.353	.92	.536
College			.84	.288	.77	.284	.84	.321	.85	.356	.88	.481
Professional degree			.84	.348	.81	.416	.90	.590	.86	.461	.94	.748
(PhD, MD, etc.)												
Age			.99	.261	1.00	.994	1.00	.595	1.00	.964	1.00	.791
Marital Status												
Divorced			1.54	.006	1.19	.662	1.65	.004	1.46	.025	1.65	.003
Widowed			2.20	<.001	9.70	.003	2.37	.000	2.35	<.001	2.59	<.001
Never Married			1.92	.037	.86	.880	1.86	.295	1.68	.123	2.02	.035
Income			1.00	.599	1.00	.809	1.00	.501	1.00	.180	1.00	.641
SES Ladder												
Middle			.61	.015	.58	.116	.71	.125	.69	.088	.70	.107
High			.40	<.001	.41	.012	.51	.004	.47	.001	.44	.001
Food stamps/SNAP			1.11	.269	.75	.347	1.03	.887	1.16	.434	1.04	.846
Table 5 continues on the next page	ge											

Table 5 (cont'd)												
Regression Models												
	Mod	lel 1	Mod	el 2	Mod	iel 3	Moo	iel 4	Moo	iel 5	Mo	del 6
	OR	Р	OR	р	OR	р	OR	р	OR	р	OR	р
Social Support												
Spouse Positive					.74	<.001						
Spouse Negative					1.23	<.001						
Children Positive							.88	<.001				
Children Negative							1.18	<.001				
Other Family Positive									.91	<.001		
Other Family Negative									1.22	<.001		
Friends Positive											.90	<.001
Friends Negative											1.23	<.001
Note: Dependent variable for a	all Models	s is Dich	otomous	Lonelin	ess.							

Logistic regression results for the interaction effect of social support on the relationship between setting and loneliness is presented in Table 6. Only the interaction between setting and positive social support from children is significant. This suggests that the effect of positive support from children varies depending on the setting (nursing home, home with previous home care, or home only). Additional analyses suggest the effect of positive support from children is stronger for those in a nursing home or living at home with care than for those at home only.

Table 6		
Interaction Models		
	OR	p-value
Setting x Social Support		
Spouse Positive	1.098	.416
Spouse Negative	1.002	.978
Children Positive	1.172	.021
Children Negative	.981	.696
Family Positive	1.015	.720
Family Negative	.923	.193
Friends Positive	.987	.785
Friends Negative	1.050	.426

### **Qualitative Data**

Fourteen interviews were conducted over a five-month period (April 2017 to September 2017). Interviewees in the qualitative data reported demographic information as part of the preinterview process and this is presented in Table 7. Average age was 76 years, six interviewees were female and eight were male.

Table 7			
Demographic dat	a from qualitative	interviews	
ID	Age	Gender Identity	Current Living Arrangement
002	71	Male	Home
004	75	Female	Home
006	91	Female	Nursing Home
007	70	Female	Nursing Home
008	74	Female	Home
009	91	Male	Home
010	68	Male	Home
011	76	Male	Home
012	86	Male	Home
015	69	Female	Nursing Home
016	65	Male	Home
017	63	Male	Nursing Home
018	86	Female	Nursing Home
019	82	Male	Nursing Home

Almost 50% of interviewees indicated that they were not emotionally lonely and all but one of these came from the in-home setting. Thirty-seven percent of interviewees were socially lonely and overall, twelve interviewees identified themselves as experiencing some loneliness based on the scale. The lowest score on the Lubben Social Network Scale (indicating a smaller social network and perceived social support), was 8/30. Table 8 below summarizes the responses to the assessment questions using the De Jong Gierveld Loneliness Scale and the Lubben Social Network.

Table 8				
Emotional, Socia	l, and Overall Lo	oneliness and Social Net	twork	
	Emotional		Overall	
ID	Loneliness*	Social Loneliness*	Loneliness*	Social Network*
At home				
002	1	0	1	16
004	1	0	1	16
008	0	1	1	25
009	1	0	1	24
010	0	0	0	21
011	0	1	1	21
012	1	0	1	26
016	0	0	0	11
Nursing home				
006	2	0	2	11
007	1	1	2	29
015	0	2	2	19
017	3	2	5	8
018	1	0	1	29
019	1	0	1	22
*Lower scores are	e indicative of lo	wer levels of loneliness	5	
†Higher scores ar	e indicative of m	nore perceived social sur	pport	

## **Primary and Sub-Primary Themes**

Four primary themes emerged from the qualitative interviews and the primary and sub-

primary themes are described in Figure 3. Additional contextual information from the interviews

is also provided. Both summary and direct quotes, the voice of the interviewees, are included.

Theme 1: Social Support Expectations and Perceptions.
Sub-theme 1a: Expectations of Social Support.
1ai: Lack of consideration of social support.
1aii: Self-reliance as expectation.
1aiii: Expected use of technology.
1aiv: Expectations based on social network.
1av: Expectations based on previous experience.
1avi: Lack of discussion as part of discharge.
Sub-theme 1b: Perceptions of Social Support.
1bi: Positive influence of social support.
1bii: Different kinds of social support.
1biii: Perceived self-reliance.
1biv: Use of technology.
1bv: Negative social support.
Theme 2: Differences Between Expectations and Perceptions.
Theme 3: Loneliness.
Theme 4: Themes Beyond Loneliness.
Sub-theme 4a: Choice of recovery setting.
4ai: Recovery setting assumptions.
4aii: Decision-making of others.
4aiii: Previous experience.
4aiv: Discharge experience.
Sub-theme 4a: Hospital stay.
Sub-theme 4b: Questions about discharge.

Figure 3 - Themes and sub-themes of qualitative data

#### **Theme 1: Social Support Expectations and Perceptions**

The interview segment in which expectations of social support following discharge were discussed included direction to think back to the hospital discharge experience and to state or imagine what expectations they had regarding social support during recovery. Interviewees initially indicated they had not thought about social support. Some interviewees talked about self-reliance as an expectation, others mentioned using technology to access social support, and still others focused on their social network and previous experiences. For the most part, interviewees did not report specific discussions with hospital staff, family, or others about what to expect during recovery regarding social support.

All interviewees were able to describe their current perceptions of social support. Perceptions of current levels of social support varied and included positive social support, different kinds of support beyond that provided by in-person visits (self-reliance and technology, specifically), and negative social support. In both the expectations of support and perceptions of current support, the use of technology as a means to access social support came out naturally as a sub-primary theme in many interviews.

#### Sub-theme 1a: Expectations of Social Support

Interviewees' identification of expectations of social support were often discussed in the midst of answers about perceptions. Reflection on this topic was clearly difficult given the circumstances of discharge and interviewees being ill, in pain, or worried about next steps. In addition, without the context of discussion by discharge staff specifically about social support expectations, it was hard for interviewees to think about what they did or might have expected:

When I came home, I was like, disoriented. (004)

I was so out of it. I had no thoughts at all about anything. (017)

I was getting so much thrown at me that it is hard to remember. (018)

This led to conversations about the types of social support that could have been expected and interviewees, for the most part, were able to identify different expectations they recall having or might have had upon hospital discharge and contemplation of recovery.

The types of social support interviewees recall expecting or imagining they would have expected was preceded by a discussion of their lack of consideration of the topic at all. This was a common answer to the initial question about expectations and led to some interviewees asking why they had not thought of the issue or why hospital staff did not bring it up.

**1ai: Lack of consideration of social support**. Most interviewees answered the question about expectations of social support upon discharge by saying they had not really considered it:

I didn't think much about it, I guess. I just thought I was going home. (004) They didn't talk about it...it wasn't part of the process. (010)

When asked to dig deeper into their expectations interviewees stated that they did not expect support. Their explanation for this appeared to come from many areas including a feeling of self-reliance, use of technology to reach out if support was needed, and an expectation that no one needed to talk about the support they would have, it would just be there, as it had always been.

**1aii: Self-reliance as expectation.** Some interviewees specifically talked about their expectations for social support being low because they expected they would take care of themselves. Others talked about not needing social support from friends, family, or professionals and being satisfied with having no or few visitors:

I wouldn't have felt bad if I didn't have anybody. (002) I knew I would have social support. I didn't think I needed it. (009) In the end, I'm responsible for myself. I'm not going to run around saying hey I had a heart attack, would you be available if I need ya? (011)

One interviewee talked about being on her own at home and being anxious for professional support to stop:

Because to me it'll be just an additional burden. I mean they mean well and they probably will do well but I'll be glad when they're done. Then I'll get back to my own routine. (006)

This is contrasted by the expectations of another interviewee who expected the opposite:

When I go home now I'm going to have caregivers come. But there's a, there's a good part to that and there's a not good part to that. Some caregivers I've experienced this, are talkative and want to be friendly. There are some that come in and do what they have to do and out the door they go and they don't want to be, and I'm the personable one. (007)

These are two examples of the differences interviewees described in their expectations, whether they had thought about it or not. For most, however, they said they had to imagine what they might have expected given that it was not brought up as a consideration at hospital discharge.

**1aiii: Expected use of technology.** Interviewees talked about using phone communication, calls and texts, to access social support after discharge. Interviewee 004 talked about reaching out to friends for comfort:

[Talking about activities after surgery] Afterwards I called a lot of friends. They were all there. (004)

Others, including Interviewee 009, talked about expecting to use the phone to reach out to others: *I knew all I had to do was pick up a phone and I would have food, help, assistance, physical assistance, whatever I needed. (009)* 

The use of the telephone was common in interviewees' talking about how they would see themselves accessing social support following discharge.

**1aiv: Expectations based on social network.** The breadth and depth of an individual's social network played a role in the expectations of some. Most interviewees talked about networks of family and friends they could rely on following their hospital stay, in whatever recovery setting they found themselves in:

Well, a lot of people said if you need to go somewhere, I'll drive you. (004)

I expected my husband to be the primary helper. (008)

I have a very, very close church family. (009)

That's where all of our support group is now. All of our friends are up there. We have a nice support group up there. (010)

*My son and daughter in law who live down in the basement and my wife. My son is a critical life paramedic and my granddaughter is a registered nurse. (012)* 

However, even in acknowledgement of a supportive social network, interviewees talked about not having expectations at all:

It's just me and my wife. And she's, like, great. So, I really don't need anybody else. But, I really don't have any expectations that other than my kids, they better call once in a while and check on me. (016)

**1av: Expectations based on previous experience.** Interviewees, some of whom had previously been a resident of the nursing home where the interview took place, another nursing home, or had had home care in the past, expected that they would receive the same levels of support from the professionals who had helped before:

*I knew I would have support here. They would help me through it and they would give me all the help I need. (007)* 

I had gone through this before, and I knew that the home health care people were going to be coming. (010)

I know a lot about support. I'm a recovering alcoholic and it took me a long time. You either get the program or you don't. And so everything's that way. (011)

These experiences were reflected in other interviewees who had had prior experience with recovery.

**1avi: Lack of discussion as part of discharge.** Interviewees were asked about conversations they had with professionals, family, or friends regarding social support. Most said they had not had any conversations that included the issue of social support as a consideration during discharge:

The hospital didn't do anything, or talk to me about anything dealing with loneliness or depression, or are you going home to friends, or are you going home to be alone. I don't think we talked about that at all. (010)

When asked if they would have liked to talk with discharge staff about social support, many interviewees agreed that they would:

*I think it might have been nice, it is kind of like saying oh that would be a luxury, but it did not seem like a necessity. (008)* 

Interviewees were not unanimous in their belief that conversations with hospital staff about social support following discharge would have made a difference in their choice of recovery setting. Often this was a conversation in the context of not being asked where they wanted to spend their recovery. These conversations then led to interviewees' current perceptions of social support.

#### Sub-theme 1b: Perceptions of Social Support.

Interviewees provided insight into the benefits and costs of perceived social support in their setting. Most individuals noted the positive influence of social support, whether it is from family, friends, or professionals. Within the context of positive social support, interviewees talked about relying on self for support and the use of technology as part of accessing social support. Interviewees could describe how they would feel with more or less social support than they were currently receiving and what that would mean to their recovery. There were comments

by interviewees in both settings about the negative aspects of social support, in getting little social support, not getting the right kind for them, and in getting too much social support. There was some reflection on how much social support was needed and there was little consensus on the meaning of "much."

**1bi: Positive influence of social support.** Professional social support was a common theme from both recovery settings. Whether it was support provided in person or over the phone, interviewees in the home setting were happy with the professional support they received:

There was a nurse out of [Hospital] that would call me. Ask how I was doing. If I needed anything. She, you know, I had her phone number to call her even later if I wanted to call her. Very nice. (002)

My step-daughter wanted me to be sure that I had a nurse and rehab at the house. And so I'm getting that yet. And, uh, I guess I just count on the nurse and the rehab. (004)

Interviewees in the nursing home setting talked about the positive influence of professionals: *Like I say, the young girls and the older people that work here they're 100% plus. (006) So, I'm comfortable, uhh, with the people that are here and like I said, some of them are more like family to me than my own family. They'll go out of their way to bring me something I might need. (015)* 

The majority of interviewees clearly identified the family, friends, and professionals who provided them with positive support. They also talked about other ways they felt supported during their recovery.

**1bii: Different kinds of social support**. In talking about the influence of more or less social support, there was diversity in thought about what effect that would have on the individual. Many interviewees, both at home and in the nursing home, talked about more social

support leading to fewer physical difficulties at home. For example, Interviewee 004 thought she would be doing better if she had had more social support:

...*in the beginning...getting these pills...it would have helped me. (004)* Others talked about there being no difference if he was getting more or less social support:

I'm a pretty outgoing guy. I don't have a problem. [I'm] not overwhelmed, don't feel like I'm not getting enough. [Talking about the influence of support on recovery] It wouldn't have made any difference. (002)

Social support was described by some participants in terms of the activities they engaged in to stimulate their relationships with others or in lieu of their relationships.

So, I've read a lot. I did a lot of catching up on books.

I have my garden and my flowers and I can talk to them. (007)

Some interviewees used language related to their activities to describe how they would continue relationships:

*I stop for coffee and...they celebrate Easter with us. (002)* 

I'm going home with good feelings and when I got flowers blooming in the garden and too many to watch die I'll bring them here. (006)

We went to a concert in the park. We're part owners in the brewery...so we went to the brewery. (010)

**1biii: Perceived self-reliance**. Interviewees talked directly about relying on themselves for their own support in their current situation:

I'm very content with myself. I don't have a lot of needs, I don't have a lot of social needs, but I enjoy them very much. But I'm sort of self-contained, I guess you could say. Um, self-assured? Maybe? But I don't need to be with people. (009)

*I feel comfortable that if I needed something, I could, ya know, boom, get it real quick.* (011)

I'd just as soon no one comes. (016)

Others talked about having to rely mostly on themselves because there was no one else:

I have no friends. I mean anyone I was friendly with is dead. (006)

This answer, from Interviewee 006, was given in the context of talking about not participating in available activities, even knowing they were there, and concentrating on rehabilitation in order to go home.

**1biv: Use of technology**. Interviewees frequently talked about using technology to access social support:

On the phone you can talk to people. A lot of people would call. Very supportive even if they are out of town. (004)

I have family in the area, they're farmers and they're busy with harvesting. But I know that any time I needed anything, I could get on the phone and in 15 minutes, there'd be somebody here. (009)

I get text messages and calls and, uh, but like I said, they don't live here. My kids live somewhere else. (016)

Even during an interview, Interviewee 002 interrupted the interview a few times to take phone calls which he described as being from family, friends, and a tenant.

Interviewee 017 talked extensively about the use of technology as a means to access social support:

Technology is good to me. [Regarding the computer being supportive] Oh, definitely. It's the only way I know what's on TV. I use it for email. Different computer groups I belong

to. Facebook. You know, stay in contact with people. If I have problems with my computer, I can look up...a lot of times I'll buy something and they don't come with directions, so I'll go on line and get the manual for a product [On Facebook] I read what the family is doing and that. (017)

**1bv:** Negative social support. Interviewees talked about their feelings related to negative social support: friends, family, and professionals who did not meet expectations or who caused stress or bad feelings. Interviewee 004 talked about having "broken heart syndrome." This was a term used by her physician to explain the cardiac illness she had. She described the physician telling her, and her confirmation of the information from on-line sources accessed later, that her illness was related to the negative social interactions she had had with the family of her second husband:

Well, you see, my husband passed away about a year ago. And, uh, his family, of course, being a second marriage, let's put it this way, they weren't very kind. And, so, I had to go through other stresses on top of all that, and then, up, I guess what it is, is that I'm a very sensitive person. I take people's difficulties to heart. And, if I could help them, you know. I'm that kind of person.... And, even more stress and all, trying to well, relocate back in the house. (004)

Interviewee 004 seemed to be relating her cardiac illness to previous perceptions of negative social support that influenced her feelings about her recovery both before returning home "I couldn't count on them" and after she returned home "I have a lot of other family I can call."

Others talked about friends or family members who were overly solicitous, to the point that they were bothersome:

*I have one relative who is kind of bugging me. She called my cell twice yesterday and then I did not respond. (008)* 

If anything there's been too much support. Ah, it tires me out. (101)

Even with that, however, the interviewee expressed appreciation for someone caring about her.

#### **Theme 2: Differences Between Expectations and Perceptions**

For most interviewees, their perceptions of social support were the same or better than what they had expected. Interviewees described the difference between expectations and perceptions in a positive way:

*The difference is I got more than what I thought.* (002)

*Oh, there is such a tremendous difference. (006)* 

I had high expectations and they've all been met, yes, they have. (007)

I don't know how it would be any, how it could be any better. I'm getting a lot more now than I might have expected. (015)

Some interviewees used more neutral language, and still expressed little or no difference between what they expected and what they perceived they were currently receiving regarding social support:

I'm very comfortable with what I've got. (009)

I didn't expect a lot but I expected some and we've been getting it. (012)

I'm getting what they, what I expected and it's been going good. (018)

One interviewee agreed that expected social support did match current perception. She also talked about her experience of balancing expected support from a close friend and not having that come through. Another friend, one not as close, stepped in and provided additional care and support that was not expected, reportedly balancing the expectation and perception, even if it was not from the expected source:

[Referencing the expected support] I thought I would have heard from her, at least a text or something. My other friend called when I hadn't expected her to. (008)

Two of the nursing home residents talked about the brevity of social interactions in the context of the difference between expectations and perceptions. These two interviewees talked about expecting longer conversations with staff and visitors. Both said that they would like conversations that lasted "a little bit longer" than just a few words during care or when someone was walking past the door. Interviewee 017 talked about not knowing what to expect as far as social support went, but wishing that there was more social support than he was currently receiving.

### **Theme 3: Loneliness**

The direct loneliness question was asked of all interviewees at the end of the interview and after explaining the purpose of the interview as quality of life, specifically loneliness. A definition of loneliness, the difference between expectations and perceptions of social support, was provided. All in-home and four of the six nursing home interviewees, when asked the direct loneliness question, expressed that they were not lonely. One nursing home interviewee said he was lonely at night and another said he was lonely.

For those who said they were not lonely, with no qualifiers, interviewees just said "no" they were not lonely:

*No. You can be with somebody and be alone. I went for a long time alone. (015) No and I credit that from within. (016)*  Interviewees who qualified their answer of not being lonely used other descriptions besides loneliness as not feeling great about their situation but not being lonely. One interviewee before he said he was not lonely had some ambivalence about what he was experiencing:

I don't know if it is lonely or boredom you know. I can only just watch so much TV. And I'm a movie guy. And I'd quit smoking, I was a little edgy then. (002)

[When asked if she was lonely] No, I've just been tired. (006)

Upon further reflection, Interviewee 002 thought it was more boredom and frustration at an inability to drive that more clearly described his feelings, rather than loneliness. Interviewee 019 said he was not lonely during the day, but felt lonely at night. He talked about this loneliness in the context of missing his wife.

Only one person interviewed, Interviewee, 017, said he was lonely. When asked what it meant to him to be lonely, he talked about having to catch people in conversation; that staff and visitors are mostly in and out doing a task. He talked about needing to say what he wanted to others very quickly in order to have any kind of interaction:

To have a conversation with a nurse, I have to wait for them to come in and give me my medication. And, you have to catch them while they are doing it. Otherwise, they are gone. I mean, but it's their job. And, they're understaffed. And the more time I take from them, the less time they have for somebody else. (017)

Interviewee 017 talked about not being able to help others, as he had done in the past, and that this might be a contributing factor to his feelings of loneliness:

I used to do some of that stuff a lot [help others with technology]. I used to do some of that stuff online with people. I learned all my knowledge online. And ways to go to a computer group, and we'd do stuff back and forth. And, I've got where I can't sit up and do it that much. I take spells now. And it is hard for me to be in the position. And, I've got pain constantly. So, I'm not as focused as I used to be. And, I guess sometimes when I get my CO2 too high, I get kind of loopy. So I can't give help anymore.

While he did not know, specifically, what would need to happen in order for him not to be lonely, he did talk about something he might consider to increase his interactions with others:

One thing I may could do is tips and tricks. Like I can hook my computer up to the TV there. And, uh, you know, if they are interested in learning different things. I can take my laptop down there and plug it into the TV in the dining room. And, I could give classes there. But not that many people have computers here. (017)

#### **Theme 4: Themes Beyond Loneliness**

In order to prepare the interviewee for a retrospective discussion of expectations at discharge, the interview, was designed to ask the interviewee to recount their hospital admission and stay experiences. Interviewees were also asked to provide insight into their discharge experience, including questions they may have wanted to ask at the time of discharge. This preparatory material, while not specifically relevant to the topic of loneliness and expectations and perceptions of social support, provided interesting insight that is relevant to future study, policy analysis, and professional social work practice.

#### Sub-theme 4a: Choice of Recovery Setting

Interview responses from both the nursing home and in-home settings followed similar patterns and the sub-themes noted below were brought up in both the home and nursing home settings. The semi-structured interview directed interviewees to think about their discharge process. The discharge process questions led to discussion with all interviewees about their recovery plans. Interviewees reacted to questions about choice by, for the most part, saying they

were not given one: *There was no discussion on what I would rather do (015)*. None of the interviewees expressed the idea that they participated fully in conversations about where they would spend their recovery. Many identified that assumptions about their recovery were made by professionals, family members, and by the interviewee themselves. Specifically, interviewees used the word "assumption" in their description of how recovery setting was chosen or how they were told where they would spend their recovery. Some talked about family or friends having influence in their discharge destination; some found this a positive experience while others appreciated their being able to trust someone else with the decision. A few interviewees had had previous experiences with recovery and were able to talk about their discharge process based on that previous experience in comparison to their most recent discharge. All interviewees commented, positively, negatively, or with a mixture of both, on their discharge experience overall. These sub-primary themes are presented below.

**4ai: Recovery setting assumptions**. Most interviewees indicated that there was a preconceived notion, or assumption, about where they would spend their recovery. This was true both for individuals recovering at home and those recovering in a nursing home. They described the reasons in multiple ways, all of which resonated with the assumption being made, by the interviewee's family, and/or by the professionals overseeing their discharge, about where to spend their recovery.

I believe it was an assumption and perhaps I was saying when will I go home. (008) There was no question about that I was coming back home (009) It wasn't an issue. I was doing so well, um, there was no real purpose in discussing it (010)

They just understood I was going home. (012)

There was no discussion on what I would rather do. (015)

I was going home. That was all there was to it. (016)

Interviewee 006 noted that "...I didn't have much choice really." when asked about recovering at home rather than in a nursing home. She said she was told, as were three of the other interviewees from the nursing home setting (015, 017, 019), that rehabilitation was needed and thus a nursing home placement was required. Each of these statements from interviewees was followed by a probe asking if rehabilitation at home was an option. Facial expressions, tone of voice, and verbal responses from all four interviewees indicated feelings of confusion:

*Q*: "What kind of conversation was there about going anywhere else for rehabilitation, so to your home?"

R: Rather than here, none. (019)

Interviewee 015 said that she was not "Howard Hughes" and so was not able to consider rehabilitation at home. She acknowledged knowing about equipment that could be used to help facilitate home rehabilitation; however, she dismissed the idea of recovering at home by saying she needed more help than could be provided by family. This same sentiment was common across interviewees in the nursing home. Most indicated they felt they needed more help than could be provided at home, even if the equipment or services were available:

Well, I couldn't walk so I live alone so I didn't have much choice really (006) And I needed to [go to a nursing home] and my husband preferred that I come to rehab too because he really can't handle me alone. (007)

Well, they said I wasn't ready to go home yet, because my walking was still a little wobbly. And that's why my daughters picked this place for me to come. (018)

Interviewee 002 addressed the issue of negative feelings if recovery had taken place in a setting other than home. This sentiment was echoed by other interviewees who talked about how different things would have been and this was also mentioned by those recovering in a nursing home. Compare Interviewee 002 with Interviewee 015:

I think it would have been worse if I'd have been in a home, you know, a nursing home. Because at least here, it is my surroundings. (002)

That was the original plan, for me to go home. But I was just renting a house so, and there was nobody there so, we just decided it would be good to stay here. (015)

**4aii: Decision-making of others**. Interviewees from both settings talked about family and professionals making decisions for them regarding their recovery setting. Some interviewees were satisfied with this, while others expressed frustration with how their recovery setting was chosen for them. One interviewee described wanting to leave it up to others:

It's overwhelming. At that point, I was just where I didn't want to carry on a decisionmaking conversation. (017)

For this particular individual, this led to family making the decision. Family members, often daughters or daughters-in-law, choosing the recovery setting was a common sentiment expressed by those going home and to the nursing home from the hospital:

My daughter-in-law is a nursing home social worker. She made all of the arrangements for me to come home. (002) My daughter works for [Nursing home] so we just decided it would be good to stay here.

(017)

My daughters picked this place for me to come. (018)

One interviewee was able to override the decision made by a family member and assert her own choice:

Well, my step-daughter did say I could come and stay with her...but that seemed silly. Because you know, I live here (004)

An interviewee from the nursing home setting said she was told by staff where she would be going:

Well they told me they were going to take me to the nursing home. (006) Others, while not indicating that a particular person made the decision for them, talked about a lack of options:

I felt bad about the whole situation and I didn't have much choice. (006) They pretty much told me. They might have asked me "are you going home?" It might have been in passing, like, are you going home, or is your wife taking you home? Maybe. I'm not sure. I don't remember that. (016)

You don't always get to do what you want to do. You have to do what is needed. (018)

**4aiii: Previous experience**. Previous experience with recovery played a role in many interviewees' decision-making and expectations regarding recovery setting. Interviewee 006 talked about the previous experience she had with her husband in a nursing home:

I saw at the nursing home my husband was put in, I saw people half in and half out of wheelchairs just sitting there. Nothing. Just a piece of, of body in a chair. (006)

This experience provided her with a context of expectation for the kinds of interactions she might have when she got to the nursing home for her own rehabilitation. Despite this previous experience, or perhaps even because of it, Interviewee 006 reported that she perceived the social

support she received in the nursing home as significantly better than what she expected. She said she does not feel like she is an object:

[Talking about another person seen during therapy] Even to a patient that's in a wheelchair...they touch their shoulder, how are you today. I mean they're making contact with patients. 006

Others talked about their previous experiences, both at home and in the nursing home, as influential in their choice of recovery setting:

I was already familiar with [Nursing home] because I had been here the first time so I knew I wanted to come back here and I was excited to come here. (007) I had been through this before. I knew what to expect. (010) They asked me and I said I would like to come to [Nursing home] because I was here a year ago and I was more than happy. (019)

Other interviewees talked about a lack of any context or previous experience with recovery as making the prospect of recovery more difficult:

[Referring to the nursing home] It's an unknown to me. So I felt like hell. Cause I didn't know what I was up against. (006)

**4aiv: Discharge experience**. Interviewees described varying experiences with the hospital discharge process. These included very good experiences, moderate experiences that included both positive and negative experiences, and descriptions of negative experiences. A common theme was expressed by many of the interviewees that identified speed of discharge as a contributing factor to negative discharge experiences.

Interviewees described their discharge experiences in the context of the semi-formal interview question "tell me what your discharge experience was like." Interviewees indicated positive experiences with staff preparing them for next steps in recovery:

They went through the process. This I could do and couldn't do. (002) Oh, it went smoothly enough. (009)

I don't have anything to complain about. They waited for somebody to have a wheelchair. They gave me directions before all that on what I was supposed to do and not do when I got home. (010)

Moderate experiences were framed in terms of the interviewees' desire to leave the hospital:

*I just wanted to get out of there. (015)* 

I wanted to get out of there as soon as possible. (017)

These comments were made with no specific animosity toward the hospital or the staff. The tone of voice and facial expression of interviewees making these comments were calm. It did not appear as though they wanted to leave the hospital because of a negative experience there:

I was just rushing along to get out of there. I got out of the hospital about 4 or 5 days early. (015)

Negative experiences of the discharge process included problems with length of time "it took forever" and "they were late". One interviewee described it this way:

They do it [discharge] like a matter of course like you're in a factory and you're going through the line. But they don't say "well how are you doing", or "this will be fine". (004)

Additional comments about the length of wait time from when they were told they could leave until all items were complete included descriptions of needing to remove tubing, have a physician's assistant complete an examination, and needing prescriptions written to give to the interviewee. Still others described problems with particular services which caused delays in leaving in a timely fashion or problems with communication:

The only issue was and that's the pharmacy at the hospital screwed up. They had to get their money right away. I didn't have any money with me. And the guy that come to pick me up he paid them and I paid him back. But I looked at the medicine and they have [the wrong address]. (002)

Well, the discharge was a little complicated because the intention was for me to leave I think fairly early on Saturday morning. My husband was there thinking he was ready to take me and so I felt uncomfortable about him sitting for hours. Finally, the nurse said, um, he [the physician's assistant] was really busy and he just saw you yesterday, so he thinks you are good to go. (007)

These kinds of difficulties made the experience more stressful for interviewees, as evidenced by tone of voice (raised pitch, talking faster), facial expression (frown), and body language (waving hands around). Other interviewees described the frustration of not receiving clear directions for showering, eating, driving, and accessing additional care and services following discharge.

Interviewees also described the discharge process as being so fast, they had no time to process their expectations:

*Well, everything was going too fast. It was just push, push, push, to get me in a nursing home. (006)* 

Some were not told that they were being discharged until they were on their way to the recovery setting.

#### *I was put in [Hospital] transport and driven over here. (006)*

All of these experiences reportedly contributed to the interviewees' initial feelings about their recovery setting. In addition, these experiences made recollection of the expectations they had for social support more difficult. This was evident during the portion of the interview when interviewees were asked to recall their expectations for social support following discharge.

#### Sub-theme 4b: Hospital Stay

Interviewees talked equally about positive and negative hospital experiences. Both those who went on to recover at home and in a nursing home talked about their stays in hospitals around the Great Lakes Bay Region as including elements that are at both ends of the experience spectrum:

Well it was good and bad. (006)

One interviewee suggested some changes in hospital staff would be beneficial:

They could get some staff that had a little bit of heart. It would help. (006)

There were positive comments about the staff of the hospital:

The nursing staff that was there, there were a lot of males. And they were more geared for tenderness for the patients than the females. (006)

The nurses were absolutely superlative. (009)

I thought the hospital did a good job. (011)

At the negative end, Interviewee 006 spoke for others when she said, "They have no time, they have no time for you."

#### Sub-theme 4c: Questions About Discharge

When asked if interviewees had any questions that they had at discharge, a number said that they felt their questions were answered:

Somebody came and told me what was what, you know. (004)

I may have asked the, ya know, some incidental questions, but I felt that, ya know, I paid close attention to what they were saying and I didn't think that there was, ya know, an area that they didn't cover that I needed to ask. (011) It was pretty good, we went over a lot of things that I could or could not do. (012) [When asked about conversations about going home] I hate to say it, but I don't think so. (016)

Others talked about feeling like they did not have time to ask questions due to the fast pace of the discharge process or because the hospital staff did not have time to address them:

They don't have time to do that. They aren't capable. (006) It [talking about social support] needs to be done when you're released from either the hospital, rehab, or whatever. That needs to be done definitely, I agree. (007) I did not ask anyone if I could drive. That was a question I had when I got home. And after a day or two, I just decided I would drive. (008)

Most interviewees agreed that having time to ask questions was or would be helpful in their comfort at leaving the inpatient setting.

#### **Interviewer Observation**

A number of items, relevant to this inquiry, were observed but not specifically talked about in the interview. These items relate to environment and perceived socioeconomic status of interviewees as observed by the interviewer. While these are not necessarily supported by individual interviewee's words, they are relevant to the interview data collected in so much as they inform the reader of context of setting for both the interviewees in nursing homes and at home. The influence of environmental context, including the region, rural vs. urban areas, and

availability of health care services was apparent in many of the interviews. The interview did not include questions, formal or informal, regarding education, occupation, or income. However, the interviewer noted the perceived socioeconomic status of interviewees. Finally, this research study is focused on differences between nursing home and in-home settings. Interviewer observation of these differences is also provided.

**Environmental context**. Interviews were conducted in interviewees' homes or in the nursing home. One interviewee asked to meet at a local restaurant. In two of the instances of interviews in nursing homes, the interviewees were planning to stay in the facility permanently, although this had not been the initial plan. The Great Lakes Bay Region includes both urban and rural areas. The home interviews were conducted in both, while the two nursing homes were in suburban areas.

The nursing homes themselves are considered both rehabilitation and long-term care facilities. One is more modern than the other, with furnishings, décor, and equipment that is well-maintained. The other facility was also clean and free of odor; however, the building and décor are both older, lending to a more well-worn appearance. One of the six interviewees had a private room, while the other five were semi-private. One of these semi-private rooms appeared to have no additional residents, while the others had a visible presence of another person living in the room.

**Perceived socioeconomic status**. While no direct questions were asked about education, occupation, or income, there were clues, in both the conversation and the environmental context that addressed issues of socioeconomic status. The homes of those visited for the in-home interviewees were well maintained and in nice areas of urban or rural settings. Yards were well maintained, visible cars were of late model years, furniture was not particularly worn, and there

were no particular odors. In only one of the homes was this not all true. That interviewee described the home she lived in as one she had owned for more than 50 years. She described it as comfortable and one that allowed her to do the kinds of things she liked to do. The interviewee who was interviewed in the restaurant mentioned two homes, both of which were described as being in nice neighborhoods. The home that was being used for recovery was described as having beach front property, multiple rooms, and great views. These descriptions and observations, in addition to the speech patterns and word usage of the interviewees, led the interviewee to believe that they enjoyed a moderate to high level of socioeconomic status.

For the six nursing home interviews, interviewees described their homes as in more rural areas with few neighbors. One stated that they had been renting a home previously. All described their home environment as older. Personal room furnishings were scarce in two of the nursing home rooms and there was little context for perceptions of their socioeconomic status beyond clothing and language use. Both of these individuals were dressed and spoke well. For the other four interviewees, their descriptions of their homes were couched in terms that left the impression of older homes with few resources.

#### CHAPTER 5

#### DISCUSSION

#### **Research Questions, Secondary Data Analysis, and Thematic Interpretation**

This study focused on the difference in loneliness experienced by individuals recovering from hospitalization in a nursing home and at home. The results from quantitative and qualitative data analyses are presented in this chapter and are organized by the research questions posed:

- (1) How do individual reported levels of loneliness compare for older persons with cardiac illness who are at home versus in a nursing home?
- (2) How do socio-demographic characteristics (age, gender, ethnicity/race, marital, and socioeconomic status, etc.) influence the patient reported levels of loneliness?
- (3) How does perceived social support influence reported levels of loneliness?

As a mixed-method exploratory study, qualitative data are used to contextualize the quantitative results. The discussion of each research question is structured around qualitative themes and the results of the secondary data analysis are discussed in the context of the thematic interpretation found in the qualitative data analysis. These, in turn, are applied to each of the research questions to address the overall exploratory goals of this research study. Discussion of the research questions is followed by interpretation of the results in terms of the Health Belief Model (HBM). It is here that the results are discussed in terms of the "why". Why were interviewees in either setting? What cues to action or knowledge did they have access to when facing hospital discharge? What was the context of their decision-making (or lack thereof)? Attributing cause, analyzing expectations and perceptions, and understanding knowledge and cues to action, were integral to the qualitative interviewes and much was learned from these data

about how decisions are made and to what extent interviewees participated in their own health decisions.

**Research question one**. The first research question explored the possibility of differences in experienced loneliness across different settings. Current research is lacking in this area and thus much of the information known about loneliness in different settings comes from non-comparable samples from more than one study (Bondevik & Skogstad, 1996; Grenade & Boldy, 2008; Pinquart & Sorensen, 2001). Results of the secondary data analysis found mixed results. The regression modeling tested setting, demographics, and social support. The first model, the difference in loneliness between settings, found a significant difference. Persons in the nursing home were more likely to be lonely than individuals who reported being at home with previous care. Persons at home with previous care, in turn, were more likely to be lonely than those who had not experienced either situation (home only). These findings are consistent with previous research which found that living in a nursing home was associated with higher loneliness (Pinquart & Sorensen, 2001).

Additional models, adding demographics and perceived social support, eliminated the difference in loneliness based on setting. None of the other models found a difference between settings in experienced loneliness. This finding refutes previous literature which found that, controlling for demographic factors, there was a difference in loneliness between those in a nursing home and those in the community (Nikmat, Hawthorne, & Al-Mashoor, 2015). This finding indicates that the difference in loneliness may not be related to the setting (nursing home or in home) but is, instead, attributable to other factors such as gender, marital status, education, income, or perceived socioeconomic status. Specifically, this study found that persons who were not married (widowed, divorced, etc.) and women were more likely to be lonely. This is similar
to previous research which also found differences in gender and marital status to be associated with loneliness (Cohen-Mansfield, Hazan, Lerman, & Shalom, 2016). The findings of this study using the secondary data can be contextualized using the qualitative interviews.

Only one interviewee in the qualitative data indicated loneliness. This individual, in the nursing home setting, spoke explicitly of being lonely. This statement of loneliness was supported by the assessment measuring both emotional and social loneliness. This individual identified himself as having a general sense of emptiness, missing having people around, feeling rejected and not feeling close to enough people. His score was the highest of all the quantitative interviewees for both emotional loneliness and overall loneliness. His responses during the interview were given with sad affect and tone of voice. He talked about being treated, by his family, as a child who could not take care of himself and the challenges of this role reversal. He wanted more interaction with staff and visitors and talked about a 30-minute conversation with a former neighbor as the best conversation he had had in years. Previous research has suggested that individuals who feel lonely lack significant others to whom than can talk, particularly family and health care professionals (Drageset, Espehaug, & Kirkevold, 2011). These responses, both to the assessment questions, the interview and the direct loneliness question, were unique in the sample. While this interviewee was living in a nursing home, it is not clear if it was the setting or other aspects of his situation that contributed to his loneliness. In this sense, his experience illustrates the complexity of loneliness and the ways in which setting alone, as in the quantitative data, may not be a sufficient risk factor for experiencing loneliness.

Regarding the assessment data collected during the qualitative interviews, no one from the in-home setting described themselves as lonely. No one from the in-home setting scored above a "1 – More or less" on the emotional, social, or overall loneliness measure. None of those

from the in-home setting talked about a negative difference between their expectations and perceptions of social support following hospital discharge. Finally, all the in-home interviewees described their current circumstances in mostly positive terms, with appropriate facial expression, tone of voice, and body language. Any in-home interviewee who did talk about wanting different support, did so to illustrate how they wanted to get back to their own lives, to stop needing help and support from others, rather than as dissatisfaction with the support itself.

In the nursing home group, the one individual who said he was lonely was not the only interviewee to talk about differences in expectation and perception. Another interviewee said, while he was not lonely most of the time, he was lonely at night due to not being able to sleep with his wife. When asked to describe what this meant to him, the interviewee said that his wife's decline due to Alzheimer's disease made life more difficult at night. He was not used to sleeping alone and he felt alone and lonely at night. This is consistent with his assessment results where he indicated that he missed having people around him. Other nursing home interviewees also reported feeling like they wanted others around them, both in the assessment and during the interview. Interviewees, both at home and in the nursing home, said that they missed family members and friends, even though they felt like they had visitors who came to see them. Again, these findings suggest that setting alone may not contribute to feelings of loneliness.

One area that was interesting in the qualitative interviews was the influence of professionals on interviewees' expectations and perceptions. When asked directly if they were lonely, many interviewees in the nursing home setting talked about how the professionals (nurses, CNAs, therapists, and others) made them feel like a part of their family. They talked about the importance of having those professionals in the nursing home setting available to talk to, to share with, and to care about. This was not as prevalent in the in-home setting. While some

interviewees in the in-home setting shared positive feelings about follow up visits or calls by professionals, these comments did not rise to the level of the feeling expressed by the nursing home interviewees. This suggests that having professionals involved may reduce the risk of loneliness. These findings are consistent with previous research on the significance of professional relationships as protective factors which reduce loneliness (Drageset, Espehaug, & Kirkevold, 2011). Slettebo (2008) found that individuals who lack professional relationships in the nursing home setting are at greater risk for loneliness.

In summary, the quantitative and qualitative findings must be interpreted with much consideration and caution. Secondary data analysis indicates that differences in loneliness may be related more to demographic characteristics than setting. While the qualitative interviews did find one individual in the nursing home who expressed loneliness, this data is not strong enough to support the notion of setting as a factor in experiencing loneliness.

These findings are both consistent with and in contradiction to previous literature, however it is important to note that there are few studies that compare these two populations on the measure of loneliness (Grenade & Boldy, 2008). Potential reasons for this are explored below.

**Research question two**. The second research question explores the relationship between sociodemographic factors and loneliness. The logistic regression of the secondary data showed that when controlling for sociodemographic factors of gender, ethnicity, race, education, age, marital status, income, subjective socioeconomic status, and eligibility for food stamps/SNAP, there were no significant differences in loneliness between setting. This suggests that differences in loneliness by setting are driven by other factors than setting alone. In particular, gender, ethnicity, marital status, and subjective socioeconomic status (SES) had significant influence on

loneliness. Qualitative interviews and interviewer observations confirmed some of these findings. Additionally, the findings on gender and subjective SES are consistent with previous research (Pinquart & Sorensen, 2001)

In the secondary data sample, women were more likely than men to experience loneliness. The difference in the experience of loneliness in this study between men and women, with women having a greater likelihood of loneliness, is not in line with some previous research on persons in the nursing home (Drageset, Espehaug, & Kirkevold, 2011), but is consistent with other studies that show women at greatest risk for loneliness (Beal, 2006). However, the experience of Interviewee 019, who talked about missing his wife, is consistent with findings of research by Drageset, Espehaug, and Kirkevold (2011), in that men who are married and are in a nursing home may experience greater feelings of loss from being without their spouse. de Jong Gierveld (2004) found that men find much of their support through their spouses, while women may be protected from loneliness through other means of social support.

Persons who were Hispanic were more likely to experience loneliness. A study of loneliness in community dwelling older Mexican-Americans found that loneliness is present in that population (Gerst-Emerson, Shovali, & Markides, 2014). However, the study did not indicate that persons of Hispanic ethnicity experienced loneliness to a greater extent than did non-Hispanic older adults.

The impact of marital status, particularly for those who reported being widowed, was very strong, with individuals who were widowed two times more likely to report being lonely compared to those who were married. Persons who reported being divorced and never married were also more likely to be lonely than those who were married. This supports previous findings from Cacioppo et al. (2000) that found that individuals who had experienced the death of a

spouse were more likely to be lonely. Being without a spouse, either through death, divorce, or never having been married is related to increased feelings of loneliness compared to married persons (Berg, Mellstrom, Persson, & Svanborg, 1981; Drageset, Espehaug, & Kirkevold, 2011). Findings from this study are consistent with previous literature with interviewees who were widowed at greatest risk for loneliness (Andersson, 1998; Drageset, Espehaug, & Kirkevold, 2011; Theeke, 2014).

Research by Pinquart and Sorensen (2001) described persons of low socioeconomic status as being at greater risk of loneliness. Results from this study are mixed in this area with objective measures of socioeconomic status, education, and income, having no significant impact on loneliness, while subjective socioeconomic status as measured by the MacArthur Scale of Subjective Social Status, was significantly related to increased loneliness, such that those reporting lower social status reported more loneliness. This is consistent with previous literature examining the relationship between self-perception of social status and functional decline in older adults (Chen, Covinsky, Cenzer, Adler, & Williams, 2012) and may be related to social support which will be discussed in more detail in question three.

Qualitative interview interviewees differed somewhat on gender and age, however all interviewees were White/Caucasian and non-Hispanic. Questions about marital and socioeconomic status were not asked directly. These items were observed by the interviewer and talked about by the interviewees during the course of the semi-structured interview. Interviewees in the nursing home were slightly older than those at home and more men were at home than in the nursing home. As with the secondary data sample, this can be explained based on life expectancy, with women tending to live longer than men in general (Kochanek, Murphy, Xu, & Tajada-Vera, 2017).

In terms of marital status, only one interviewee talked specifically about being a widower. He did not talk in terms of sadness or loss, but more about being self-reliant and happier now that he had a "little friend" who came by and with whom he engaged in social activities. In addition, while an interviewee in the nursing home had not experienced the death of his wife, he did talk about her in terms of great loss, given her diagnosis of Alzheimer's disease. Hurley and Volicer (2002) and others have likened the experience of Alzheimer's disease by caregivers as a series of "little" deaths (p. 2328) with loved ones who have the disease being described as the "walking dead" (p. 2328). This experience of partial widowhood in the face of Alzheimer's may explain this interviewee's feelings of loneliness "only at night." Many individuals, in both settings, described their spouses as being instrumental in their recovery and in both their expectations and perceptions of social support following discharge. This relationship will be explored in more depth in discussion of research question three.

Socioeconomic status (SES) was also a complex construct in the qualitative data based on interviewer observation and interviewee comments. There were no specific questions about income, education, or other measures of SES in the qualitative interviews. However, the observations by the interviewer, detailed in Chapter 4, were illustrative of aspects of the socioeconomic status of interviewees. Upon reflection of the home environments of at home interviewees it appeared that most, if not all, lived in neighborhoods with homes that were high in value (multi-storied, multi-roomed homes with large, well-maintained yards). Only one of the Interviewees at home lived in a section of the Great Lakes Bay Region that is now considered low income. In the past, that section of the community was considered middle class with houses that were well-maintained and most individuals with union jobs that put them in middle to uppermiddle class income brackets. This interviewee described her home as one she had lived in for

decades. Her comfort in her home environment was obvious in the way she moved around the space, picked up objects to show to the interviewer, and talked about her home. These observations combined to give the impression that interviewees from the in-home setting were at least in the middle of the subjective socioeconomic status measure. This was not true for those in the nursing home.

Again, determining the socioeconomic status (SES) of individuals in the nursing home was made difficult without specific measures. However, interviewees talked about their homes as being in rural areas, not owning their own homes, and described their homes as small or not conducive to recovery (lack of space for equipment or wheelchair use). The interviewees themselves had few possessions that would allow for an evaluation of their income or education by the interviewer. However, the overall impression of fewer resources than individuals in the home setting went beyond the physical space (nursing home vs. home) and draws on the interviewer's experience in long term care facilities in the Great Lakes Bay Region, including having provided services as an ombudsman, home care social worker, and through the Alzheimer's Association. The two facilities are known to the interviewer as ones that accept Medicaid payment for long term stays, an indicator of persons having fewer economic resources, compared to facilities that accept Medicare-only or are private pay. That is not to say that any of the interviewees were known to be using Medicaid as a payment source. However, it may be an indication of the socioeconomic status of the interviewees or at least gives the impression, to this informed interviewer, that individuals who are in the facility long term have fewer financial resources.

Overall, the question of the effect of demographic variables on the experience of loneliness between settings was most significant, both qualitatively and quantitatively, for issues

of marital and socioeconomic status. The qualitative interviews illustrated that widowhood may have some subjective components that are associated with the illness or deterioration of a spouse rather than their death alone. Additionally, the subjective socioeconomic status (SES) is a complex variable that goes beyond income and education as factors of SES. How a person feels about where they are in terms of SES appears to have a great deal of relevance to their health status in general and their feelings of loneliness in particular. It is through an understanding of social network (having a spouse or not) and social support that these findings may be more clearly understood.

**Research question three**. The third and final question addresses the influence social support has on loneliness. Specifically, how is perceived social support related to loneliness and does perceived social support moderate the influence of setting on loneliness. Responses to positive support questions suggest that interviewees on average feel understood, are able to rely on others, and can talk with others about problems. Responses to negative support questions indicate interviewees sometimes report that they feel that others are too demanding and critical, that interviewees feel let down by others, or that others are annoying.

Positive and negative support were significantly related to experienced loneliness in ways we would logically expect. Positive support was associated with decreased loneliness; negative support (feel criticized, let down, etc.) increased the likelihood of experiencing loneliness. This was true, to varying degrees, with each of the social support sub-scales. Social support in general seems to have an influence on the experience of loneliness. To understand the potential moderating influence of social support on the relationship between setting and loneliness, an interaction effect was examined.

Of the eight interaction effects tested, (setting by positive and negative support for each source of social support) only one result was significant. Positive social support from children significantly modified the relationship between setting and loneliness. While positive support from children decreases the likelihood of loneliness, the effect is stronger for those who are in nursing homes or are at home and have previously had home care than it is for those at home without care.

The meaning interviewees in the qualitative interviews gave to the support they received is consistent with the findings from the quantitative data analysis. Uniformly, interviewees talked about their social support, both in terms of expectations and perceptions. Among those who did not feel lonely, it was clear that the social support they received from spouses, children, family, friends, and professionals was instrumental in their positive feelings about recovery. This information was clarified extensively during the interviews leading to a conclusion that individuals who felt understood in terms of their need for support and their feelings about recovery were less lonely. Professional support was often likened, particularly in the nursing home, to "family", leading to conclusions that this level of support is as relevant and helpful as that of others. For the two interviewees who indicated that they were lonely, both of whom were in the nursing home setting, not having the support of a spouse and not being heard or understood by family and friends reportedly led to loneliness.

Negative support was discussed in terms of individual family members and friends who did not provide the support needed or expected. Interviewees who talked about being let down by friends or family and having this experience offset by others who they had not expected to be supportive also indicated not feeling lonely. Family, who interviewees said called too much (made too many demands), were balanced by those who used technology to communicate,

resulting in the perception by the interviewees that they were getting enough social support and that "too much", in the form of more friends and family stopping by or seeming to make too many demands, might be detrimental to their recovery.

Interviewees noted during the interviews that their children play an important role in feelings about recovery. From children being helpful in setting up discharge plans and recovery settings, to their frequent visits and calls, more interviewees talked about their children's involvement in their recovery than any of the other three groups (spouse, other family, or friends) which is consistent with the quantitative results. This finding, that positive support from children moderates the relationship of setting and loneliness, is particularly interesting given previous research on the subject. Drageset, Espehaug, and Kirkevold (2011) found a negative correlation between the amount of attachment older adults in nursing homes had with their children and loneliness such that individuals with more attachment to their children were less lonely. Bondevik and Skogstad (1998), in one of the few studies comparing older adults in nursing homes and community settings, found that the frequency of contact with children was related to less loneliness in community dwelling older adults but not those in nursing homes. Only in the instance of the nursing home interviewee who said he was lonely were children talked about in negative terms. In that instance, the interviewee talked about a role reversal that resulted in his child telling him how to live. The impact of this negative support by his child was described as disappointing and was accompanied by a sad affect, frowns, looking down, and a low and depressed tone of voice. This, too, is consistent with previous literature, which found that older adults, both in the community and in nursing homes, who desire more frequent or more positive contact with children, were more likely to be lonely (Bondevik & Skogstad, 1998).

For the question of the relationship between social support and loneliness, including the moderating influence of social support, the quantitative results are mixed, with only positive support from children moderating the relationship between setting and loneliness. The quantitative and qualitative data clearly illustrated the positive impact of social support from all categories, with the addition, in the qualitative interviews, of professionals who were viewed as both family and friends. Positive support, particularly from children, helps to reduce experienced loneliness across settings while negative support contributes to greater feelings of loneliness. This is consistent with previous research that ties perceptions of social support to physical and mental health (Baigi, Hildingh, Virdall, & Fridlund, 2008; Dong, Beck, & Simon, 2009).

# **Rigor in Qualitative Data**

As noted in Chapter 3, rigor was attended to using principles described by Padgett (2008), Yardley (2000, 2017), and Smith, Flowers, and Larkin (2013). Participants were interviewed in their own settings in thirteen out of fourteen cases. The one interviewee who requested a different location was asked to choose a setting they were comfortable in. This attends to the second principle of Yardley (2000, 2017) and the need to address sensitivity to comfort of the interviewee. In addition, the attention paid to the requirements of the IRB approved method, ensuring the rights of the interviewee are prominent in all interaction.

The principle of transparency and coherence is maintained through the detailed literature review, method section, results, and discussion. Details of both data gathering and analysis are clearly spelled out and allow for a reproduction of the study if desired by another researcher. In addition, the documents (audio recordings, transcripts, field notes, data file) are maintained in a coherent and logical fashion which would allow for a detailed audit by IRB should that be

necessary. This attention to details also addresses the trustworthiness described by Padgett (2008) by ensuring that there is nothing hidden about any of the steps in this qualitative inquiry.

# **Health Belief Model**

Throughout the results and discussion above, the data collected and analyzed is presented in terms of expectations and perceptions of social support. This is the language of the Health Belief Model (HBM) and speaks directly to the definition of loneliness used both in previous research and in this study. The HBM helps to understand the results discussed above in terms of why loneliness may differ by setting, why marital status and subjective socioeconomic status impact loneliness, and what role social support may play in influencing loneliness. The Health Belief Model includes three main areas relevant to understanding how one might experience a health behavior: perceived susceptibility, perceived threat, and perceived benefit vs. barriers. Loneliness can be viewed as a health behavior according to the definition by Gochman (1997) which includes personal attributes including expectation and perception. Thus, understanding how and why expectations and perceptions are viewed can shape what we know about the etiology and outcome of loneliness.

The HBM starts with understanding the susceptibility individuals have to a health issue, and the potential threat that issue has on individual health. Interviewees in the qualitative data, from both settings, stated clearly that at no time did anyone in the hospital talk to them about their risk for loneliness. They did not recall much if any conversation about social support during their recovery. When asked if talk about either of these issues might have made a difference in their choice of recovery setting, there was much agreement that it would not have made a difference. However, many conceded that not having talked about social support or risk for loneliness meant that they could not have used that in decision making. Gochman (1997) found

that professionals were often instrumental in patients' understanding of and engagement in health behavior. The qualitative interviews are consistent with this finding as interviewees talked about professionals in the hospital setting making assumptions about their discharge and recovery setting. Many of the interviewees in the at home setting and the majority of interviewees in nursing homes said that they ended up in their current recovery setting because of assumptions made by the hospital staff. Such assumptions then negated the need for discussion of the availability of social support, the susceptibility of individuals to loneliness, and the potential health consequences.

The findings of this study, that there is a lack of discussion or even consideration of loneliness as a health threat, and the absence of evaluation of available social support appear to be areas that, through use of the Health Belief Model, could be altered. Most interviewees did not feel they were given a choice of recovery setting or even that it was overtly discussed. This would seem to indicate that discharge decisions were made, if not by family (which occurred in some cases in this study), by the hospital professionals responsible for discharge planning. How do they make those decisions? Evidence from this study, existing literature (see Popejoy, Moylan, & Galambos, 2009), and previous experience of the secondary researcher suggests that decisions about recovery setting are based on finances and influenced by speed, not a consideration of risk of loneliness nor available social support.

The findings of this study, suggesting that positive social support has a protective effect against loneliness and negative social support can increase risk of loneliness, must be interpreted cautiously given the cross-sectional nature of the sample. It is reasonable to assume that these results are a function of other variables not studied in this research. These may include the strength and meaning of the relationship with the object of social support (spouse, children, other

family, and friends) and well as the role children play after the death of a spouse. Other potential variables include how the older adult views their life circumstance and the life events that have resulted in transitions.

Nevertheless, the correlations between positive and negative social support and loneliness suggest that relationships with others is an important component of experienced loneliness. This is consistent with previous research that found interactions between close relationships and loneliness (Tiikkainen & Heikkinen, 2005), including those of children (Routasalo et al., 2006) and friends (Eshbaugh, 2009). Interviewees talked about their relationships with professionals as being like that of family, which may help explain the results of positive social support by other family as being significantly related to experienced loneliness, although quantitative data was not available for this study specifically on support from professionals. Previous research on the positive influence of professionals in the nursing home setting found that residents with these relationships had more positive outcomes than those without (Bergland & Kirkevold, 2006; Tseng & Want, 2001). These results have implications for social work practice, education, policy, and future research and will be discussed in Chapter 6.

# Limitations

Study results must be considered within the context of several limitations. Limitations of the secondary data analysis included the inability for direct comparison of individuals in the study and in the qualitative interviews based on hospital discharge. It was not possible to know if the setting, nursing home or at home with home care, was directly related to recent hospital discharge. It is possible to say that both groups, those in the secondary data sample and those in the qualitative sample, had experienced life events that are considered risk factors for loneliness.

Thus, the direct correlation of the secondary data set to the qualitative interview sample was challenging.

There were also limitations related to the sample of the secondary data set, as noted in the Missing Data section of Chapter 3. The positive spouse social support data had 1466 missing cases. Two-hundred forty-two of those cases reported as being married and thus it is expected that they would have answered the spouse social support questions. It is possible that these 242 participants did not understand the question or were not currently living with their spouse and thus did not answer the question. It is also possible, as with the interviewee in the qualitative data who described his wife with Alzheimer's disease as "no longer there", that participants in the secondary data analysis felt similarly. Regardless, eliminating these participants from the full analysis would have resulted in non-comparable samples and thus they were left in the full sample. Similar results for children, other family, and friends are noted in Chapter 3 – Missing Data and are explained as missing because participants did not have children, other family, or friends. It is also possible that a similar explanation given for spouse, is relevant for these categories as well.

The majority of nursing home residents (62.9%) use Medicaid to pay for their nursing home stay as compared to 9.2% of home care users (Harris-Kojetin et al., 2016). Because there was a finding in this study that indicated an effect of perceived socioeconomic status on the outcome of loneliness, it is important to consider that many of the nursing home residents, both in the quantitative and qualitative samples, may have been poor. Poverty has many other confounding influences, including gender and race (Luhmann & Hawkley, 2016; Rico-Uribe et al., 2016; Theeke, 2009). The data presented in this study did not address the confounding of the effect of poverty on loneliness. However, because the findings indicate that there is little

difference between nursing home and at home settings regarding loneliness, this may not be a particular issue of concern.

In addition, the qualitative sample was not differentiated between those who were in the nursing home for a short term rehabilitative stay and those who were there long term with no specific plan for discharge. It is possible that there is a difference in loneliness between these two groups within the nursing home and a further analysis of the differences between these two groups is warranted. Again, because there was little loneliness expressed in the nursing home segment of the sample, this issue may not be of particular concern.

IPA encourages a "forgetting" of previous codes with review of every new transcript (Smith, Flowers, & Larkin, 2013). This process was difficult and may not have resulted in a pure case-by-case coding. The secondary researcher did, at the conclusion of the review of each transcript and the resulting thematic coding, reflect on the codes to attempt to identify if the codes emerged inductively from the transcript or, if the themes were a result of deductive application of previous established themes. This process did, occasionally, result in some recoding, but may not have provided for truly independent analysis of each interview. The addition of another person or persons to review the transcript and audio tapes and a discussion to reach consensus, may have helped strengthen the resultant themes.

Interviews were conducted one or more weeks after discharge from the hospital. The nature of the questions required interviewees to recall expectations of social support while going through the discharge process. Many interviewees talked about the discharge experience being fast and this, in combination with recall from a few weeks into their recovery, may have made it more difficult for them to recall their expectations accurately. This limitation was attended to during interviews with attempts to create a context which would make recall easier. However, it

is possible that their recollection of their expectations for social support did not reflect the reality of what they really felt at the time.

### **CHAPTER 6**

# **CONCLUSION**

# Implications

The goal of this study was to explore the relationship between loneliness and setting using demographics and social support as clarifying variables. Chapter 6 provides a view of the implications of the study findings on Social Work Practice, Education, Policy, and Research.

## **Social Work Practice Implications**

Much evidence exists pointing to the difficulty of treating loneliness. Current interventions, including friendly visitors and group therapy, show limited evidence in support of effectiveness. Researchers have concluded that reducing feelings of loneliness is not easy and requires a multifaceted approach (de Jong Gierveld & Fokkema, 2015). Results from this study are consistent with those findings and have a number of implications for social work practice in numerous settings. In addition, while this study suggests that setting alone may have little effect on risk for loneliness, it seems clear that loneliness is a risk factor for persons who are experiencing some type of life changing event (nursing home transition and/or the need for assistance in the home) and should be addressed as a matter of course when an older adult is faced with these life transitions.

First, loneliness needs to be understood and addressed as a risk factor for negative health outcomes. Social workers who work with older adults and in hospital and other health care settings are well placed to address the issue of loneliness in direct practice. Informing older adults of their risk for loneliness is an important consideration based on findings from this study. Research using the Health Belief Model to change other health behaviors (Saunders, Frederick, Silverman, & Papesh, 2013), has found that the mechanism for change was increased knowledge

about risks of poor health outcome and empowerment of the individual to be able to affect change in their own health behavior. Previous research on loneliness has found that changing cognition, specifically changes in expectations, may be an appropriate intervention strategy (Mann et al., 2017; Masi, Chen, Hawkley, & Cacioppo, 2011). This would fit with the Health Belief Model (Jopling, 2015) and findings from this study that showed when expectations met perceptions, interviewees in the qualitative data were not lonely. Other approaches to address loneliness in older adults, including groups that are widely appealing (beyond just "socialization" or targeted loneliness) (Mann et al., 2017), and those that target specific behaviors identified as enhancing social contacts (Pettigrew & Roberts, 2008), require additional research and may be informed by the results of the study described here. Of particular note, in this study, was the parallel to the Pettigrew and Roberts (2008) qualitative study that found activities such as meals, reading, and gardening appear to help stimulate positive social interaction and alleviate feelings of loneliness. Interviewees in this study talked about all three of these activities as helpful to their perceptions of current social support.

Second, social workers practicing in hospital discharge settings should be aware of how socioeconomic status, speed of discharge, and assumptions about recovery setting impact discharge planning and transition to recovery setting. Much evidence has been presented (see Chapter 2) regarding the discharge process and the method by which recovery setting is chosen as a function of discharge planning. Research by Popejoy, Moylan, and Galambos (2009) and others have found discharge planning to be a rushed process, often without the input of the individual being discharged. These findings were confirmed by this study and speak to the need for social workers involved in the discharge planning process to spend more time consulting the older adult and informing other members of the health care team about the importance of doing

so. It is also important for social workers in these settings to think about issues beyond what they believe to be the older adults' socioeconomic status and what they think the older adult wants regarding recovery. Previous research on discharge planning (Popejoy et al., 2015) found that it is most often professionals who make discharge decisions. This finding was supported in this study. Social workers are often the professionals responsible for these decisions and, based on the findings from this study, may be making assumptions about recovery setting based on their own ideas of what the older adult wants and/or needs and what socioeconomic resources they have available. Many interviewees in this study clearly said that discharge decisions were made without discussing it with them. In the absence of these discussions about what the older adult wants and what resources are available, decisions are made by social work professionals on behalf of older adults that may not be in the recovering individual's best interest.

A third implication is the importance of incorporating risk for loneliness into assessment of older adults. Social workers engage in assessment of older adults in various settings and at various times in an older adult's life. Adding assessment for loneliness to an already full battery of assessment instruments, particularly during times of stress or urgency, may be difficult. However, the benefit of understanding the risk of loneliness for older adults, namely better health outcomes which could reduce hospital readmission or use of health services (Calvillo-King et al., 2012; Drageset, Espehaug, & Kirkevold, 2011), may outweigh the added time. Interviewees clearly stated that they thought talking about social support prior to their discharge would have been helpful and yet this was rarely, if ever, done. Knowing that an older adult may be at risk for reduced function in Activities of Daily Living and/or transition to a care facility brings an opportunity to begin assessment and discussion of the risk of loneliness. In addition, social workers in the position to know risk factors of traumatic life events may also be poised to help

shape expectations, potentially using some of the intervention strategies found in previous work and mentioned above.

Finally, the use of technology as a way to access social support was an unexpected finding in this study. The implications of these findings could be a change in the way telemedicine is used to address issues of quality of life. Assessment of the ease with which an older adult uses technology, from land-line phones to computers to hand held devices such as cell-phones and tablets, may help better understand the access to social support that is available. Talking to older adults about how they have used technology in the past and then finding ways to enhance those skills may give older adults at risk for loneliness additional outlets for meeting expectations of the social support available to them. A study by Pettigrew and Roberts (2008) found that older adults, in addition to using in person social support from friends and family, also used rituals of eating meals as a way to ameliorate loneliness. The potential of using this as an intervention strategy to improve social engagement with others, perhaps through technology that connects individuals while they are eating a meal, may be another change in social work practice suggested by these research findings. However, use of technology does not have to be high tech. As interviewees indicated, phone calls, texting, and email were all ways of accessing social support.

Changes in social work practice, in assessment, discharge planning, treatment based on changing expectation and managing perceptions, as well as the use of technology, are all potential outcomes from this research. The quantitative data suggests that difference in loneliness outcomes between settings may be driven by factors other than setting itself, while the qualitative data provides meaning to those results and moves the discussion forward toward changes in social work practice. It is also important to consider how these findings can influence

social work education that shapes new and seasoned practitioners, and policy that shapes the context of social work practice.

# **Educational Implications**

It is clear from the qualitative interviews conducted as a part of this study that loneliness and social support are not often thought of by practitioners when considering recovery. Knowing that the results of the secondary data analysis show a difference in loneliness based on setting amplifies the need to consider the implications of loneliness as a part of social work education. The risk of loneliness and the need to assess for social support is an important addition to the social work curriculum at all stages, Bachelor, Master, Doctoral, and continuing education.

At the Bachelor level, an understanding of traumatic life events and the potential risk for loneliness may be added to the beginning generalist curriculum. While Human Behavior and the Social Environment are no longer prominently mentioned in the Educational Policy and Accreditation Standards (CSWE, 2015), there remains a call to engage, assess, and intervene with individuals across the lifespan. By adding a specific understanding of the impact of loneliness on older adults, social work students will be better prepared to engage in informed generalist practice at the Bachelor level.

Social work students at the Master's and Doctoral levels also need to understand these relationships, of loneliness, social support, and setting, in order to provide clinical intervention and to engage in policy practice and research. At these more advanced levels of practice, social work students are often targeting their education toward a particular population or issue. Incorporating content on loneliness and the contexts in which loneliness occurs, social work educators can better prepare these advanced practitioners for work with older adults.

Continuing education is another area that could benefit from the results of this study. In Michigan, licensed social workers are required to obtain 45-hours of continuing education credit every three years to remain in good standing. There is currently no requirement to seek out education about older adults in general, nor the issue of loneliness. A review of the current faceto-face continuing education offerings listed on the Michigan Social Work Continuing Education Collaborative website (2017) found twelve (of more than 200) educational programs that specified information on older adults. None of the offerings targeted an understanding of loneliness. This dearth of information on a topic with a growing evidence base that points to risk for the older adult population is troubling. Adding continuing educational offerings based on information found in this study may be beneficial to the many social workers in the State of Michigan.

Incorporating understanding of loneliness in an interprofessional curriculum that includes education of other health professionals such as direct care staff, doctors, nurses, occupational and physical therapists, kinesiologists, health scientists, and numerous others can only help in the care and treatment of older adults. Interprofessional education is designed to prepare health professionals for engaging in care of individuals in a collaborative team environment (Buring et al., 2009). Because health professionals often share responsibilities for various aspects of older adult care, including when older adults are facing a traumatic life event which may increase their risk for loneliness, a common understanding of the risks of loneliness and the health implications of untreated loneliness are important. Educational activities and programs that give all health professionals the same information about loneliness and social support may help reduce overall loneliness as collaborative teams address these issues together.

# **Policy Implications**

The policy implications of this study are numerous. First, current long-term care policy emphasizes aging-in-place, including an emphasis on returning individuals from nursing homes to the community (World Health Organizations, 2015). This ideological position, a worldview that sees great benefit in emphasizing the least-restrictive environment and assuming that the home environment is the most conducive to successful aging, has resulted in policies at the national, state, and local levels that encourage older adults to remain in the community. Results from this study seem to support this policy, at least in the context of loneliness. Differences in loneliness are related to demographic differences rather than differences in setting. Based on results of this study, and supported by previous studies (Cohen-Mansfield, Hazan, Lerman, & Shalom, 2016) on differences in loneliness as a result of demographics such as gender and marital status, aging-in-place policies should include consideration of these factors. However, more study is needed and cautious optimism is called for with regard to this seeming support of current policy.

Changes in discharge and readmission policies should be considered. Loneliness and the availability of social support were not addressed during discharge planning for the fourteen individuals interviewed in this study. While practice does not necessarily speak specifically to policy, it is a good indicator of how policy is interpreted and carried out. Current discharge practices, as illustrated by interviewees in this study, seem to be focused on speed rather than on the choice of the older adult being discharged. It is possible that discharge practices that encourage shorter hospital stays are engaged in an effort to save costs by transferring those patients with high needs to nursing homes or home with care settings. A story in the New York Times (Frakt, January 4, 2016), cited evidence from the CDC, the Journal of the American

Medical Association, and other sources to explain this policy of speedy discharge. Frakt (2016) concluded that payment to hospitals by Medicare has a relationship with shorter hospital stays. More recent Medicare policy punishes hospitals for high readmission rates (Rau, 2014). In this context in which quick discharge is supported by reimbursement policies, research such as this study which provides data on potential unintended consequences of speed discharge processes should be considered. Policies that address the potential impact of loneliness on recovery should be reviewed and/or created. In addition, policies that encourage conversations about expectations for recovery setting and of social support available should be emphasized.

Socioeconomic factors and gender are two additional variables to consider when thinking about policy implications. Understanding that socioeconomic factors, in particular the older adult's perception of their status in comparison to others, influence loneliness and possibly discharge decision-making, helps to alter or clarify current policy regarding discharge and recovery setting. It is important to consider assumptions professionals have about financial resources when engaging in discharge planning. Nursing home interviewees from this study talked about not having the resources to go home, thus needing nursing home placement. Their comments seemed to be based on what they were told by professionals. And yet, there appeared to be little difference, in therapy needs, restrictions, and needed professional support (therapy services and follow up appointments with doctors) between those in the nursing home and those at home. If decisions about recovery setting are made based on assumptions of professional discharge planners then policies are needed that emphasize exploration, with all older adults facing the need for short- or long-term recovery, of all potential resources and how the older adult perceives their options.

An additional demographic factor to consider for policy implication is the impact of gender on loneliness as well as the role women play in many aspects of care provision for older adults. Women account for the majority of both formal and informal caregiving (AARP, 2007). Aging-in-place policies, including the emphasis of the Affordable Care Act on reduction of use of nursing homes, rely on a majority female workforce to provide supports and services to older adults (Hooyman, 2015) as well as the role women play in informal, unpaid caregiving. Findings from this study reinforce the role women play in making decisions about and providing care to older adults and this supports continued implementation and development of policy that is supportive of women in caregiving roles.

Returning to the final area of the Health Belief Model with implications for policy change, cues to action, requires attention to policies that emphasize coordination of information provision, knowledge about loneliness, and opportunities to educate older adults, their social supports, and professionals about the risks of loneliness. Currently, the Affordable Care Act has encouraged the development of policy that requires education of both older adults and caregivers regarding the care they require and the options available to them for care provision (Medicare and Medicaid Program, 2017). Additional emphasis on policy that provides time and reimbursement for professionals to educate older adults on their risk of loneliness and options for recovery is needed. This study found that there is a distinct lack of education on risk of loneliness and little attention paid to exploration of available social support as older adult's face transition from the hospital. The Health Belief Model suggests that this attention, to education and exploration of options, as cues to action, could make a positive difference in the older adult's experience of loneliness as a health behavior outcome. In the last few years, with the implementation of the Affordable Care Act, additional policies focused on caregivers and the rights of older adults who need care have been introduced and implemented. Federal regulations went into effect in July 2017 that provide for increased assessment of potential caregiver willingness, skill, and availability to provide care for older adult family members (Caregiver Program Information Dissemination Act of 2017, 2017). This speaks specifically to the need to assess social support during coordination of care. This policy also ensures older adults and their caregivers receive on-going education and training regarding their care needs. Additional bills before Congress include policy aimed at the training and support for caregivers of individuals with Alzheimer's disease and related dementias, diabetes, and other diagnoses (Alzheimer's Caregiver Support Act, 2017). State legislative trends include some states creating new tax credits for caregivers that would cover expenses incurred to provide care for older adults in the community (Legislation and Public Policy, 2017). It is important to continue the current trend in developing and advocating for policies that provide for stronger rights for older adults.

# **Research Implications**

This study lends volume to the continued call, as expressed by Masi, Chen, Hawkley, and Cacioppo (2011), Mann et al. (2017) and others, for more research related to loneliness as a distinct risk factor in overall health. From the 1970's research on social support by Cobb (1976) through the 2017 meta-analysis of intervention strategies for loneliness (Mann et al., 2017), this on-going search for more empirical evidence on loneliness and social support remains necessary. This study adds to a very small body of evidence examining the difference in experienced loneliness between the settings of nursing home and at home. To clarify the results of this exploratory study, future research should seek to better understand these findings.

The use of Interpretative Phenomenological Analysis (IPA) in social work research appears to be unique. Additional research using this method and focusing on an exploration of the relationship social support plays in moderating the influence of setting on loneliness would add to the findings of this study. Specifically, the meaning older adults ascribe to their relationships with children and professionals would clarify the findings of this study and help to better understand why the positive support of children may be a moderating influence on loneliness. Additionally, the use of older adult voices to identify meaning and describe experience is an important contribution to this area of study.

The findings from this study lead to the need for additional analysis of this data, both quantitative and qualitative, to better understand the experience of loneliness. An analysis of the types of studies that could follow from these results is also in order. It may be appropriate to include clinical trials of interventions not only to address the experience of loneliness but also to understand what fiscal outcomes might occur with policy that directs inclusion of loneliness assessment, prevention, and intervention in social work practice. Building evidence-based practice strategies at the micro, mezzo, and macro levels for social workers and interdisciplinary teams is a call that comes from the findings and interpretation of the data from this study.

There is also much more to be learned about how discharge decisions are made and how assumptions and socioeconomic status plays a role in the work of discharge planning. Focus groups and surveys of current discharge planners would be helpful in better understanding the findings from this study. Using IPA, or other qualitative methods, to explore how and why discharge planners make decisions and how this does or does not fit with current policy, would be an enlightening addition to this research. Research that targets expectations at discharge, asking questions of individuals when they are in the process of discharge, and following up with

questions after discharge, may also add to the current body of knowledge of the Health Belief Model and how cues to action could influence loneliness as a health behavior.

Finally, studies that use these findings to inform possible interventions would add to the little that is known about the effectiveness of various interventions on loneliness. A recent metaanalysis of interventions aimed at reducing loneliness found that research studies that use nonrandomized groups and comparison studies had larger effect sizes than did randomized trials (Masi, Chen, Hawkley, & Cacioppo, 2011). This fits well with social work practice and would allow for the development of evidenced-based practices in real world settings. Working with local communities, in both nursing home and home-based settings, to address loneliness through interventions that address expectations and perceptions of social support would add to the body of knowledge on this topic.

# Conclusion

Findings from this study were mixed, with both secondary data analysis and qualitative interviews indicating a more nuanced difference existing in experienced loneliness than can be explained by recovery setting. Socioeconomic status and marital status, along with gender and ethnicity, play roles in determining risk of loneliness. Social support, from spouses, children, other family, and friends, influences experienced loneliness. Positive support from children has a moderating influence on the relationship between setting and loneliness, with increased positive support from children serving to decrease loneliness in both nursing home and at home with previous care settings. The qualitative results helped to clarify the quantitative findings by explaining the meaning older adults make of these differences in experienced loneliness.

The overarching goal of this study was to explore the relationship between setting and experienced loneliness and the influence demographic variables and social support have on that

relationship. This study used both quantitative and qualitative methods, specifically secondary analysis of nationally representative survey data and Interpretative Phenomenological Analysis with qualitative interviews, to better understand loneliness as a health behavior, guided by the theoretical model of Health Behavior and previous research on social support

Implications of this study include suggested changes to social work practice; education at the Bachelor, Master, and Doctoral levels as well as continuing education for licensed social workers policy at the micro, mezzo, and macro levels; and future directions in research. Social work practice may be informed by this research in the consideration of intervention strategies that speak to changing cognition, specifically expectations of social support. Additional practice strategies that encourage increased emphasis on the choice of older adults during discharge planning as well as increased focus on the risks of women for loneliness and the fact that women provide care and play roles in decision-making are also relevant based on the findings of this study. Including loneliness and the roles setting and social support play in experienced loneliness in the curriculum of formal educational programs and continuing education for social work practitioners is another implication from this study. In addition, policies that continue and enhance the current trend toward more information and education provided to older adults and caregivers, as well as those that require assessment of social support may be informed by the outcomes of this study. Finally, implications for research include the need for further understanding of the role subjective socioeconomic status plays in the development of loneliness and investigation into the discharge process in general, with an emphasis on assumptions and older adult choice. Social workers, empowered with increased knowledge such as that provided in this study, can move forward in their on-going responsibility to seek the best possible treatment and resources for vulnerable older adults.

APPENDICES

### Appendix 1 - All IRB documents

# MICHIGAN STATE

January 30, 2017

To: Amanda Woodward 222 Baker Hall

Re: IRB# x16-1624e Category: EXEMPT 2 Approval Date: January 30, 2017

Title: Understanding the intersection of loneliness and recovery setting in older cardiac patients

The Institutional Review Board has completed their review of your project. I am pleased to advise you that **your project has been deemed as exempt** in accordance with federal regulations.

The IRB has found that your research project meets the criteria for exempt status and the criteria for the protection of human subjects in exempt research. **Under our exempt policy the Principal Investigator assumes the responsibilities for the protection of human subjects** in this project as outlined in the assurance letter and exempt educational material. The IRB office has received your signed assurance for exempt research. A copy of this signed agreement is appended for your information and records.

**Renewals**: Exempt protocols do <u>not</u> need to be renewed. If the project is completed, please submit an *Application for Permanent Closure*.

**Revisions**: Exempt protocols do <u>not</u> require revisions. However, if changes are made to a protocol that may no longer meet the exempt criteria, a new initial application will be required.

**Problems**: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects and change the category of review, notify the IRB office promptly. Any complaints from participants regarding the risk and benefits of the project must be reported to the IRB.



**Follow-up**: If your exempt project is not completed and closed after <u>three years</u>, the IRB office will contact you regarding the status of the project and to verify that no changes have occurred that may affect exempt status.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.

Protection Programs Biomedical & Health Institutional Review Board (BIRB)

**Human Research** 

Community Research Institutional Review Board (CRIRB)

Social Science Behavioral/Education Institutional Review Board (SIRB)

Olds Hall 408 West Circle Drive, #207 East Lansing, M1 48824 (517) 355-2180 Fax: (517) 432-4503 Email: irb@msu.edu www.hrpp.msu.edu

MSU is an affirmative-action, equal-opportunity employer.

c: Catherine Macomber, Kyle McDaniel

# Initial IRB Application Determination \*Exempt\*

Covenant HealthCare 1447 North Harrison Saginaw, MI 48602

989.583.0000 Tel



DATE:	February 20, 2017
TO:	Amanda Woodward, PhD
FROM:	Covenant Medical Center Institutional Review Board
PROJECT TITLE:	[1023696-2] Understanding the intersection of loneliness and recovery setting in older cardiac patients
REFERENCE #:	C-17-01 Loneliness
SUBMISSION TYPE:	Response/Follow-Up
ACTION:	APPROVED
APPROVAL DATE:	February 20, 2017
EXPIRATION DATE:	February 15, 2018
REVIEW TYPE:	Expedited Review

Thank you for your submission of the following Response/Follow-Up materials for this project;

revised informed consent

The Covenant Medical Center Institutional Review Board has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this committee. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this committee.

Generated on IRBNet

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of February 15, 2018.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Pam Bonds at 989-583-6486 or pbonds@chs-mi.com. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Covenant Medical Center Institutional Review Board's records.

- 2 -

Generated on IRBNe



April 6, 2017

DATE:

(989) 964-4000 • From Midland: 695-5325 7400 Bay Road • University Center, MI 48710 • USA

TO:	Amanda Woodward, PhD
FROM:	Saginaw Valley State University Institutional Review Board
STUDY TITLE:	[1023696-4] Understanding the intersection of loneliness and recovery setting in older cardiac patients
IRB REFERENCE #:	2017MC009
SUBMISSION TYPE:	Revision
ACTION:	APPROVED
APPROVAL DATE:	April 6, 2017
EXPIRATION DATE:	February 27, 2018
REVIEW TYPE:	Administrative Review

Thank you for your submission of Revision materials for this research study. Saginaw Valley State University Institutional Review Board has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Administrative Review based on the applicable federal regulation.

#### Informed Consent is required:

Please remember that <u>informed consent</u> is a process beginning with a description of the study and insurance of participant's understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.

Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.

Once the project is completed, a close-out form must be submitted via IRBnet.

If you have any questions, please contact Julie Decker at (989) 964-4941 or jadecker@svsu.edu. Please include your study title and reference number in all correspondence with this office.

CC:

- 1 -

Generated on IRBNet

# MICHIGAN STATE

ERSITY

# Determined Not "Human Subjects"

6/6/17

#### Amanda Woodward Email: awoodwar@msu.edu

Re:

#### Determination of Human Subject Research

IRB # x16-1624e : "Understanding the intersection of loneliness and recovery setting in older cardiac patients"

#### Dear Dr. Woodward:

It has been determined that the activity described in your application to the IRB submitted May 25, 2017 does not meet the definition of "human subjects" as defined by the U.S. Department of Health and Human Services (DHHS) regulations for the protection of human research subjects.

#### Human Subject

For DHHS, "human subject" means "a living individual about whom an investigator (whether professional or student) conducting research obtains: (1) Data through intervention or interaction with the individual, or (2) Identifiable private information." [45 CFR 46.102(f)].

After reviewing the information you have provided, it has been determined that:

□ Living individuals are not involved

- □ The activity is not "about" the living individual
- I Will not obtain data through interaction or intervention or private identifiable information

You will be analyzing secondary, de-identified data from the Inter-University Consortium for Political and Social Research: National Social Life, Health, and Aging Project (NSHAP). You will not be obtaining any data through an interaction or intervention with human subjects.

Hence, your activity does not involve human subjects.

Therefore, the federal regulations for the protection of human subjects would not apply to your project and you do not need MSU IRB approval to proceed. However, please note that while MSU IRB approval is not required, other federal, state, or local regulations or requirements or ethical or professional standards may still be applicable based on your activity.

If any of these circumstances change, please contact the IRB as your activity may involve human subject research and require IRB approval.

If you have any further questions, please contact the MSU IRB office at 517-355-2180.

Sincerely,

nchel Bailey McMillan

IRB Administrator

cc: Catherine Macomber



Office of Regulatory Affairs Human Research Protection Programs

Biomedical & Health Institutional Review Board (BIRB)

Community Research Institutional Review Board (CRIRB)

Social Science Behavioral/Education Institutional Review Board (SIRB)

Olds Hall 408 West Circle Drive Room 207 East Lansing, MI 48824 (517) 355-2180 Fax: (517) 432-4503 Email: <u>irb@msu.edu</u>

MSU is an affirmative-action, equal-opportunity employer.

V14.1


IRB Office 4000 Wellness Drive Midland, Michigan 48670 Phone (989) 488-5945 Fax (989) 839-1694

TO: FROM:	Amanda Woodward, PhD MidMichigan Health Institutional Review Board
2 Internation	
PROJECT TITLE:	[1062205-1] Understanding the intersection of loneliness and recovery setting in older cardiac patients
REFERENCE #:	
SUBMISSION TYPE:	New Project
ACTION:	DETERMINATION OF EXEMPT STATUS
DECISION DATE:	June 19, 2017
REVIEW CATEGORY:	Exemption category # 2

Thank you for your submission of New Project materials for this project. The MidMichigan Health Institutional Review Board has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations. See information below:

- Renewals: Exempt protocols do not need to be renewed. If the project is completed, please submit a closure notice to the IRB.
- Revisions: Exempt protocols do not require revisions. However, if changes are made to a protocol that may no longer meet the exempt criteria, a new initial application will be required.
- Problems: If issues should arise during the conduct of the research, such as unanticipated
  problems, adverse events, or any problem that may increase the risk to the human subjects and
  change the category of review, notify the IRB office promptly. Any complaints from participants
  regarding the risk and benefits of the project must be reported to the IRB.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact Sandra Moore at 989-488-5945 or sandra.moore@midmichigan.org. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within MidMichigan Health Institutional Review Board's records.

- 1 -

Generated on IRBNet

Variable Name	Description
<u>Demographics</u>	•
Gender	Male (0), Female (1)
Interviewee or proxy interview	Yes (1), No (5)
Age 65 or older	In years (60 – 100)
Interviewee currently in a	Yes (1), No (5)
nursing home	
Last grade of school completed	In years $(0 - 17)$
Highest degree completed	0&9 – Unknown, 1&2 – GED/High School Diploma, 3&4
	Undergraduate College Degree, 5&6 Graduate Degree
Hispanic/Latino	Hispanic (1-3), Non-Hispanic (5)
Marital status	Married (1), Not Married (2), Widowed (3)
Race	White/Caucasian (1), Black or African American (2),
	Other (7)
Health Conditions	
Has a doctor ever told you that	Yes (1), No (5)
you have a heart condition	
<u>Cognition</u>	
Much of the time during the past	Yes (1), No (5)
week you felt lonely	
TICS Score – Responses to	Cognitively intact (≥5), Cognitively impaired (≤4)
question 124, 129, 151-158	
Social Support and Loneliness	
Spouse social support	Positive Perceived Social Support – Questions a – c
Living children social support	Negative Perceived Social Support – Questions a – g
Other family social support	(1=A lot, 2=Some, 3=A little, 4=Not at all)
Friends social support	
Loneliness questionnaire	Often (1), Some of the time (2), Hardly ever or never (3)
Socioeconomic ladder	X placed on a visual representation of a ladder $(1 - 10)$
Health Services	
Patient in a hospital overnight –	Yes (1), No (5)
last two years	
Has any medically trained person	Yes (1), No (5)
come to your home to help you,	
yourself – last two years	
Income and Welfare	
Income	Annual amount in \$ - Interviewee and spouse
Welfare income	Annual amount in \$ - Interviewee and spouse
Food stamp eligibility	Yes (1), No (5)

### Appendix 2 – HRS Data Variables used for Sample

## Script for Individuals Who Meet the Inclusion Criteria - Research Project Description – Site 1

You have been chosen to be a part of research on feelings about recovery and support after being discharged from the hospital. The goal of the study is to understand how where you recover affects how you feel. I would like you to complete a survey a few weeks after you leave the hospital and maybe take part in an interview. I would like to know if you want to be a part of this study.

### **Possible Questions**:

- *Why was I chosen*? The inclusion criteria for the study is people age 60 and over, with no cognitive impairment, who have a cardiac diagnosis, and who are recovering at home or in a nursing home.
  - *If the individual states that any of these things are not true*: Thank you for letting me know. If you do not meet the criteria you can throw the flyer away.
- *What if I don't want to do it*? You do not have to be a part of the research. This is only a voluntary project and you can stop at any time. You can throw the flyer away. If you decide to call the phone number on the flyer and then change your mind later, you can call back, throw away the survey if you receive it, tell the researcher you don't want to participate, and so on. None of these things will have any impact on the care you receive from McLaren Bay Region or any other health care provider.
- Will I get paid or get anything from taking the survey or doing the interview? As it says on the flyer, if you send back the survey and include your name, you will be entered into a drawing (with about 200 others) for a \$100 Visa card. If you choose to participate in the interview, you will receive a \$25 Visa card.

## Script for Individuals Who Meet the Inclusion Criteria - Research Project Description – Site 2

You have been chosen to be a part of research on feelings about recovery and support after being discharged from the hospital. The goal of the study is to understand how where you recover affects how you feel.

As you can see, the flyer explains the study and includes information on what the study is about and the opportunity to complete a survey and, if you want, an interview with the researcher, Cathy Macomber. There is a phone number on the flyer and an email address where you can contact Cathy if you would like to have her send you the survey. Cathy can also answer any questions you might have about the research.

### Possible Questions:

- *Why was I chosen*? The inclusion criteria for the study is people age 60 and over, with no cognitive impairment, who have a cardiac diagnosis, and who are recovering at home or in a nursing home.
  - 0

- *If the individual states that any of these things are not true*: Thank you for letting me know. If you do not meet the criteria you can throw the flyer away.
- What if I don't want to do it? You do not have to be a part of the research. This is only a voluntary project and you can stop at any time. You can throw the flyer away. If you decide to call the phone number on the flyer and then change your mind later, you can call back, throw away the survey if you receive it, tell the researcher you don't want to participate, and so on. None of these things will have any impact on the care you receive from McLaren Bay Region or any other health care provider.
- Will I get paid or get anything from taking the survey or doing the interview? As it says on the flyer, if you send back the survey and include your name, you will be entered into a drawing (with about 200 others) for a \$100 Visa card. If you choose to participate in the interview, you will receive a \$25 Visa card.

### Appendix 4- Site 1 Consent



### **Recovery After Hospitalization - Survey**

Catherine A. Macomber Secondary Researcher School of Social Work Department of Michigan State Saginaw V University University

y Researcher Department of Social Work Saginaw Valley State University Kyle McDaniel Covenant Employee Researcher Clinical Resource Management Covenant Healthcare

### INFORMED CONSENT FORM

### **Introduction and Purpose:**

You are being asked to participate in a research study about loneliness after hospital discharge. We want to learn about how where you go after discharge affects how you feel. There is both a survey for you to complete and, if you choose, the opportunity to participate in a follow-up interview. This consent form is to inform you about the research study, explain risks and benefits of participation, and empower you to make an informed decision. You should feel free to ask the researchers any questions you may have. You do not have to participate in the study. Participation in the study is entirely voluntary and whether or not you participate will have no impact on any treatment, payment, enrollment or eligibility for benefits to which you are entitled.

You have been selected as possible participant in this study because you are 60 years or older, you have been in the hospital because of a heart condition, you are being discharged from the hospital and you are going home or to a nursing home. We hope to enroll 400 participants. From this study, we hope to learn how where you are living after leaving the hospital affects your feelings. It should take about 15 minutes to complete the survey. If you choose to participate in a follow-up interview, that interview will take about one hour. This study is being conducted by both Michigan State University and Covenant Healthcare.

### **Participation:**

If you choose to participate in the study, your doctor will share your name, address, email address (if you have one), discharge date and destination, cardiac status, age, marital status and race/ethnicity with the research staff who will send a survey to you by postal mail or email. The survey will include questions about the help you are receiving and how you feel as you recover, and will give you an opportunity to participate in a second stage of the project, an in-person interview. If you wish to participate in the in-person interview, you will have to include your name and contact information on the survey. You will complete the survey and send it back to the research staff in the envelope provided, or you may complete the survey on-line using the internet.

You may choose not to answer any question, or request that an answer not be included in the results. Your survey responses will be grouped together with answers received from other participants in the study.

Covenant	Approved on:	February 20, 2017
Medical Center	Expires on:	February 15, 2018
IRB	Study number:	C-17-01



Your participation in the study will end at the end of the survey and/or interview. You may choose to stop at any point during the study.

### **Potential Benefits:**

Your participation in this study may help nurses, aides, researchers and other older adults to understand how where a person recovers following a hospital stay affects how that person feels, in particular, if he or she feels lonely. However, there may be no direct benefit to you by your participation in this study.

### **Potential Risks:**

There is a risk that some of the questions in the survey might make you uncomfortable. Although there are safeguards in place to protect the privacy of your information as described below, there is also a risk that your information may be improperly disclosed.

### Authorization to Use and Disclose Protected Health Information

Before any health information about you may be shared as part of this study, the researchers are required to obtain your authorization. This section helps explain to you how your information will be used or shared with others involved in the study, and what protections will be in place to protect the privacy of your information.

Researchers and research staff at Michigan State University and Saginaw Valley State University, the MSU Human Research Protection Program, and the Covenant Institutional Review Boards will use, share and receive your information for this study. Your health information may also be shared with federal, state or local agencies that have oversight of the study or to whom access is required under the law. The information that is shared with those listed above may no longer be protected by federal privacy rules.

All of your information obtained for the study will be kept in a locked cabinet and/or a password protected computer in the study investigator's locked office. Your answers to the survey will be kept separate from your name after the survey is returned. If you participate in the interview, your answers will be audio-recorded and transcribed.

Data from this study will be kept for at least three years after the project ends. All hard copies of surveys, notes, and all audio recordings and transcripts will be destroyed as soon as allowable by law. Any identifying information like your name will be kept completely separate from the data, in a separate file. Your survey responses may be used in the write-up portion of the study, but results will be presented in the aggregate with no names or identifying information. If you participate in the interview, your words may be quoted without any name or identifying information attached. No information that could identify you in any way will be released to any individuals or agencies other than the research staff,

Covenant	Approved on:	February 20, 2017
Medical Center	Expires on:	February 15, 2018
IRB	Study number:	C-17-01



unless required by law (this may include adult abuse shared during the optional in-person interview). Your choice to skip a question or to end participation will be kept confidential.

You have the right to refuse to sign this authorization. Your health care outside of the study, payment for your health care, and your health care benefits will not be affected if you choose not to sign this form. You will not be able to take part in this study if you do not sign this authorization.

If you do sign this authorization, it will not expire unless you change your mind and revoke it in writing. You may revoke this authorization at any time by sending a notice of revocation to the principal investigator as listed below.

### Your Rights to Participate, Say No, or Withdraw:

Participation is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. You may change your mind at any time and withdraw. You may choose not to answer specific questions or to stop participating at any time.

### Costs and Compensation for Being in the Study:

You will not be charged for any part of the study. A self-addressed, stamped envelope will be provided to return the paper survey. If you choose to provide your contact information, your name will be entered into a drawing for a \$100 gift card, no matter how many questions you answer or even if you withdraw from the study at a later date.

### **Conflict of Interest**

The research team has no conflicts of interest in this research study.

### **Contact Information:**

If you have any questions or concerns about the study, to report an injury, to revoke your authorization to use and disclose your information, or if you are interested in the findings from the study, you may contact the principal investigator: Amanda Woodward, 222 Baker Hall, 655 Auditorium Rd., East Lansing, MI 48824, 517-432-8702, awoodwar@msu.edu.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail <u>irb@msu.edu</u> or regular mail at 408 West Circle Drive, Olds Hall Room 207, MSU, East Lansing, MI 48824. OR Covenant IRB at 989-583-6486 or email pbonds@chs-mi.com.

Covenant	Approved on:	February 20, 2017
Medical Center	Expires on:	February 15, 2018
IRB	Study number:	C-17-01



### **Documentation of Informed Consent:**

Your signature below means that you voluntarily agree to participate in this survey and that you authorize the use and disclosure of your protected health information as described above.

Signature

Date

You will be given a copy of this form to keep.

If I choose to participate in the optional in-person interview, I understand that my interview will be audiotaped.

Initial \_\_\_\_\_

Covenant	Approved on:	February 20, 2017
Medical Center	Expires on:	February 15, 2018
IRB	Study number:	C-17-01

### Appendix 5– Survey Assessment

# Recovery After Hospitalization

### MICHIGAN STATE UNIVERSITY

### Welcome

You have been chosen as a participant in this research study because you were discharged from the hospital and are recovering from an illness. This research study is looking at your feelings about your recovery and how much support you feel you have. Our goal is to understand how where you are recovering affects how you feel. Your participation will involve completing a survey. Your responses are very important to us and we hope you will assist us by completing the questions; it should take less than 10 minutes of your time.

Your participation in this research project is completely voluntary. You may choose not to answer questions or to stop answering questions at any time. Whether you choose to participate or not will have no effect on services you might need from the hospital, nursing home, home care or community in the future. There are no anticipated risks associated with completing this survey, beyond some possible discomfort with the questions.

Your name will not be shared and your information will be presented with others and will not be identified as yours. After you complete the survey you will be given the opportunity to enter your name for a drawing to win a \$100 Visa gift card.

All information will be coded and kept in password protected computers in locked offices. The information collected will be part of a published paper on recovery following hospital discharge. The information may be presented at conferences and in peer-reviewed journals. All personal information will be confidential and kept for a minimum of three years.

If you have any concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury or problem, please contact the researcher: Amanda Woodward, 222 Baker Hall, 655 Auditorium Rd., East Lansing, MI 48824, 517-432-8702, awoodwar@msu.edu.

If you have any questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail <u>irb@msu.edu</u> or regular mail at 207 Olds Hall, MSU, East Lansing, MI 48824 OR MidMichigan Medical Center – Midland IRB at 989-488- 5945 or email sandra.moore@midmichigan.org.

\* By continuing on to the rest of the survey, you indicate your voluntary agreement to participate in this research project.

## MICHIGAN STATE

### Please tell us a little bit about yourself.

For the following Questions, please write in your answer or fill in the circle next to your answer.

- 1. In what year were you born?
- 2. What is your gender identity?
- O Female
- O Male
- O Transgender Other
- 3. Do you consider yourself Hispanic/Latino?
- O Yes
- O No
- 4. Which category best describes your race?
- O American Indian/Alaskan Native
- O Arab/Middle Eastern
- O Asian
- O Black or African-American
- O Native Hawaiian/Other Pacific Islander
- O White or Caucasian
- O Multiracial Other (please specify)
- 5. Where are you currently living?
- O Your own home
- O Nursing home Other (please specify)

## MICHIGAN STATE

### Please tell us how you feel about your current relationships.

For the following Questions, please fill in the circle next to your answer.

6. For each of the following, please think about how you currently feel and answer each question with Yes, More or less, or No.

	Yes	More	No
		or less	
I experience a general sense of emptiness	0	0	0
I miss having people around me	0	0	0
I often feel rejected	0	0	0
There are plenty of people I can rely on when I have problems	0	0	0
There are many people I can trust completely	0	0	0
There are enough people I feel close to	0	0	0

## MICHIGAN STATE

Please answer the following questions about your family and friends.

For the following Questions, please fill in the circle next to your answer.

7. Family: Considering the people to whom you are related by birth, marriage, adoption, etc...

	None	One	Two	Three or Four	Five thru Eight	Nine or More
How many relatives do you see or hear from at least once a month?	0	0	0	0	0	0
How many relatives do you feel at ease with that you can talk about private matters?	0	0	0	0	0	0
How many relatives do you feel close to such that you could call on them for help?	0	0	0	0	0	0

8. Friendships: Considering all of your friends including those who live in your neighborhood...

	None	One	Two	Three or Four	Five thru Eight	Nine or More
How many of your friends do you see or hear from at least once a month?	0	0	0	0	0	0
How many friends do you feel at ease with that you can talk about private matters?	0	0	0	0	0	0
How many friends do you feel close to such that you could call on them for help?	0	0	0	0	0	0

## MICHIGAN STATE

### **Optional Raffle Drawing**

If you would like to have your name entered into a drawing for a \$100 gift card, please provide your name and address below:

Name	
Address	
City/Town	
State	
Zip Code	
Email Address	
Phone Number	

## MICHIGAN STATE

### **Invitation for a Face-to-Face Interview**

There is a second part to this research project, a face-to-face interview; to talk to you in person about your recovery expectations and experiences. Interview participants will receive a \$25 Visa gift card at the end of the interview. You do not have to participate in the interview, however if you would like to be considered for an interview, please complete the Contact information below. If you do not want to participate in the interview, please do not fill in the information below.

\* By filling in your information below, you indicate your voluntary agreement to be contacted for the interview portion of the research project.

Name	
Address	
City/Town	
State	
Zip Code	
Email Address	
Phone Number	

Thank you for your participation.

Please use the addressed, stamped envelope to return the survey to

Catherine A. Macomber Department of Social Work 7400 Bay Rd., H245 University Center, MI 48710

### **Scale Psychometrics**

The 6-item scale includes three items related to emotional loneliness (negatively-worded) and three items related to social loneliness (positively-worded). Interviewees are asked to indicate the extent to which each statement applies to "the way they feel now." The response categories include "yes," "more or less," and "no" The three emotional loneliness items will be reverse coded so that a higher score indicates more loneliness. Positive and neutral answers on the negatively worded questions will be scored as "1," while neutral and negative answers on the positively worded questions will be scored as "1." Below is a visual representation of two sample questions, one from the negatively worded and one from the positively worded questions. The answer "more or less," therefore, is scored the same as "yes" or "no" depending on whether it is a negatively worded or positively worded question, respectively. This results in the possibility of a range of scores on emotional loneliness of 0 (not emotionally lonely) to 3 (intensely emotionally lonely) and a social loneliness range of 0 (not socially lonely) to 3 (intensely socially lonely). While it is possible to add the scores together, for the purposes of this research, the two types of loneliness, emotional and social, will be examined separately to determine if scores on the social loneliness subscale correlate with scores on the Lubben Social Network Scale. The Loneliness Scale – Short Version has been validated with samples of older adults. Internal consistency ranges from .70 - .76 (De Jong Gierveld & Van Tilburg, 20). The authors report the six-item scale to have internal congruent validity between the full six items and each of the three-item subscale measures of emotional and social loneliness (De Jong Gierveld & Van Tilburg, 2010).

### **De Jong Gierveld Loneliness Scale**

### For each of the following, please think about how you currently feel and answer each question with Yes, More or less, or No.

r	Yes	More or	No
I experience a general sense of emptiness	0	0	0
I miss having people around me	0	<b>O</b>	<u>о</u>
I often feel rejected	0	0	0
There are plenty of people I can rely on when I have	0	0	0
There are many people I can trust completely	0	0	0
There are enough people I feel close to	0	0	0

### Lubben Social Network Scale

For the following Questions, please fill in the circle next to your answer.

7. Family: Considering the people to whom you are related by birth, marriage, adoption, etc...

	None	One	Two	Three or Four	Five thru Eight	None or More
How many relatives to you see or hear	0	0	0	0	0	0
How many relatives do you feel at ease with that you can talk about pri-	0	0	0	0	0	0
How many relatives do you feel close to such that you could call on them for	0	0	0	0	0	0

## 8. Friendships: Considering all of your friends including those who live in your neighborhood...

	None	One	Two	Three or Four	Five thru Eight	None or More
How many of your friends do you see	0	0	0	0	0	0
How many friends do you feel at ease with that you can talk about private	0	0	0	0	0	0
How many friends do you feel close to such that you could call on them for	0	0	0	0	0	0

## MICHIGAN STATE

**Michigan State** 

University, together

with MidMichigan

Medical Center —

Midland, is recruiting

adults age 60 and

over who have been

discharged from the

hospital and who are

recovering from

cardiac illness (heart attack, heart failure,

heart disease, etc.) to

participate in a

research study about

quality of life during

recovery.

## **Quality of Life Research Project**

### Things to know:

### How long does it take?

The survey should take about 15 minutes to complete

### What will we do?

- You will be sent a survey in the mail or by email
- You will be asked about your friends and family, the support you receive during your recovery
- An addressed, stamped envelope will be provided for you to return the survey
- If you choose, you can include your name and address when you return the survey and you will be entered into a drawing for a \$100 gift card
- You can also choose to participate in a follow up interview where you will receive a \$25 gift card

MSU Human Research Protection Program 207 Olds Hall East Lansing, MI 48824	MidMichigan Medical Center—Midland Cardiovascular Research 4005 Orchard Dr., Rm	To participate or for more information call Cathy Macomber			
517-335-2180	02261	989-295-1894 or email			
	Mildiand, Mil 48070	macombe2@msu.edu			

## MICHIGAN STATE

### Welcome

Hello!

Thank you for contacting me about the research project. You called to give me your address and to agree to participate in the study by completing a survey.

The survey is attached to this letter. If you choose to participate, you could win a \$100 Visa gift card. If you would like to, you can also, using the survey, agree to participate in a follow up interview. For participating in the interview, you will receive a \$25 Visa gift card.

Please consider participating in this research on recovery after hospitalization. Your time is valuable and we hope you can find a few minutes to respond to our survey.

If you have questions or would like further information on the research project, please contact Catherine A. Macomber, macombe2@msu.edu, 989-295-1894.

Sincerely,

The Research After Hospitalization Team

Appendix 7 – Interview Documents

### **Recovery After Hospitalization - Survey**

Catherine A. Macomber Secondary Researcher School of Social Work Michigan State University University

### **INFORMED CONSENT FORM**

### **Introduction and Purpose:**

You are being asked to participate in a research study about loneliness after hospital discharge. We want to learn about how where you go after discharge affects how you feel. There is both a survey for you to complete and, if you choose, the opportunity to participate in a follow-up interview. This consent form is to inform you about the research study, explain risks and benefits of participation, and empower you to make an informed decision. You should feel free to ask the researchers any questions you may have. You do not have to participate in the study. Participation in the study is entirely voluntary and whether or not you participate will have no impact on any treatment, payment, enrollment or eligibility for benefits to which you are entitled.

You have been selected as possible participant in this study because you are 60 years or older, you have been in the hospital because of a heart condition, you have been discharged from the hospital and you are recovering at home or in a nursing home. We hope to enroll 16 participants. From this study, we hope to learn how where you are living after leaving the hospital affects your feelings. This study is being conducted by both Michigan State University and MidMichigan Medical Center - Midland.

### **Procedures:**

As a volunteer participant in this study, you will be involved in one individual, face-to-face interview that will last approximately 45 minutes to 1 hour (in one sitting or two, as you choose). The interview will include an introduction to the research project, and an explanation of the format of the interview, and a cognitive assessment. In the interview, you will be asked questions related to your expectations before leaving the hospital and your perceptions during your recovery. You may choose not to answer any question that makes you uncomfortable, or request that an answer not be included in the results. Whatever you decide will have no impact on any services you receive from MidMichigan Medical Center – Midland.

Your participation in the study will end at the conclusion of the interview(s). You may choose to withdraw at any point during the study and you may decline to answer any questions. You will be provided with the contact information of the investigators in case you have any questions or concerns about the study. You will receive a \$25 Visa gift card at the

conclusion of the interview. You may also request a copy of the interview transcript. If you are interested in the findings from the study, you may contact the investigators at any time.

### **Potential Benefits:**

Your participation in this study may help nurses, aides, researchers and other older adults to understand how where a person recovers following a hospital stay affects how that person feels, in particular, if he or she feels lonely. However, there may be no direct benefit to you by your participation in this study.

### **Potential Risks:**

There is a risk that some of the questions in the interview might make you uncomfortable. Although there are safeguards in place to protect the privacy of your information as described below, there is also a risk that your information may be improperly disclosed.

### Authorization to Use and Disclose Protected Health Information

Before any health information about you may be shared as part of this study, the researchers are required to obtain your authorization. This section helps explain to you how your information will be used or shared with others involved in the study, and what protections will be in place to protect the privacy of your information.

Researchers and research staff at Michigan State University and Saginaw Valley State University, the MSU Human Research Protection Program, and the MidMichigan Regional Medical Center - Midland Institutional Review Boards will use, share and receive your information for this study. Your health information may also be shared with federal, state or local agencies that have oversight of the study or to whom access is required under the law. The information that is shared with those listed above may no longer be protected by federal privacy rules.

All of your information obtained for the study will be kept in a locked cabinet and/or a password protected computer in the study investigator's locked office. Your answers to the survey, if you complete it, will be kept separate from your name after the survey is returned. Your interview will be audio-recorded and transcribed.

Data from this study will be kept for at least three years after the project ends. All hard copies of surveys, notes, and all audio recordings and transcripts will be destroyed as soon as allowable by law. Any identifying information like your name will be kept completely separate from the data, in a separate file. Your survey responses may be used in the write-up portion of the study, but results will be presented in the aggregate with no names or identifying information. From the interview, your words may be quoted without any name or identifying information attached. No information that could identify you in any way will be released to any individuals or agencies other than the research staff, unless required by law (this may include adult abuse shared during the optional in-person interview). Your choice to skip a question or to end participation will be kept confidential.

You have the right to refuse to sign this authorization. Your health care outside of the study, payment for your health care, and your health care benefits will not be affected if you choose not to sign this form. You will not be able to take part in this study if you do not sign this authorization.

If you do sign this authorization, it will not expire unless you change your mind and revoke it in writing. You may revoke this authorization at any time by sending a notice of revocation to the principal investigator as listed below.

### Your Rights to Participate, Say No, or Withdraw:

Participation is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. You may change your mind at any time and withdraw. You may choose not to answer specific questions or to stop participating at any time.

### **Costs and Compensation for Being in the Study:**

You will not be charged for any part of the study. You will receive a \$25 Visa gift card for your participation in the interview.

### **Conflict of Interest**

The research team has no conflicts of interest in this research study.

### **Contact Information:**

If you have any questions or concerns about the study, to report an injury, to revoke your authorization to use and disclose your information, or if you are interested in the findings from the study, you may contact the principal investigator: Amanda Woodward, 222 Baker Hall, 655 Auditorium Rd., East Lansing, MI 48824, 517-432-8702, awoodwar@msu.edu.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail <u>irb@msu.edu</u> or regular mail at 408 West Circle Drive, Olds Hall Room 207, MSU, East Lansing, MI 48824. OR MidMichigan Medical Center – Midland IRB at 989-488- 5945 or email <u>sandra.moore@midmichigan.org</u>.

### **Documentation of Informed Consent:**

Your signature below means that you voluntarily agree to participate in this interview and that you authorize the use and disclosure of your protected health information as described above.

Signature

Date

You will be given a copy of this form to keep.

If I choose to participate in the optional in-person interview, I understand that my interview will be audiotaped.

Initial \_\_\_\_\_

### **Contact Information:**

If you have any questions or concerns about the study, to report an injury, to revoke your authorization to use and disclose your information, or if you are interested in the findings from the study, you may contact the principal investigator: Amanda Woodward, 222 Baker Hall, 655 Auditorium Rd., East Lansing, MI 48824, 517-432-8702, awoodwar@msu.edu.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail <u>irb@msu.edu</u> or regular mail at 408 West Circle Drive, Olds Hall Room 207, MSU, East Lansing, MI 48824. OR MidMichigan Medical Center – Midland IRB at 989-488- 5945 or email <u>sandra.moore@midmichigan.org</u>.

### **Recovery After Hospitalization - Interview**

Catherine A. Macomber Secondary Researcher School of Social Work Michigan State University University University

### **INFORMED CONSENT FORM**

### **Introduction and Purpose:**

You are being asked to participate in a research study about loneliness after hospital discharge. We want to learn about how where you go after discharge affects how you feel. This consent form is to inform you about the research study, explain risks and benefits of participation, and empower you to make an informed decision. You should feel free to ask the researchers any questions you may have. You do not have to participate in the study. Participation in the study is entirely voluntary and whether or not you participate will have no impact on any treatment, payment, enrollment or eligibility for benefits to which you are entitled.

You have been selected as possible participant in this study because you are 60 years or older, you have been in the hospital because of a heart condition, you have been discharged from the hospital and you are recovering at home or in a nursing home. We hope to enroll 16 participants. From this study, we hope to learn how where you are living after leaving the hospital affects your feelings. This study is being conducted by Michigan State University.

### **Procedures:**

As a volunteer participant in this study, you will be involved in one individual, face-to-face interview that will last approximately 45 minutes to 1 hour (in one sitting or two, as you choose). The interview will include an introduction to the research project, and an explanation of the format of the interview, and a cognitive assessment. In the interview, you will be asked questions related to your expectations before leaving the hospital and your perceptions during your recovery. You may choose not to answer any question that makes you uncomfortable, or request that an answer not be included in the results. Whatever you decide will have no impact on any services you receive.

Your participation in the study will end at the conclusion of the interview(s). You may choose to withdraw at any point during the study and you may decline to answer any questions. You will be provided with the contact information of the investigators in case you have any questions or concerns about the study. You will receive a \$25 Visa gift card at the conclusion of the interview. You may also request a copy of the interview transcript. If you are interested in the findings from the study, you may contact the investigators at any time.

### **Potential Benefits:**

Your participation in this study may help nurses, aides, researchers and other older adults to understand how where a person recovers following a hospital stay affects how that person feels, in particular, if he or she feels lonely. However, there may be no direct benefit to you by your participation in this study.

### **Potential Risks:**

There is a risk that some of the questions in the interview might make you uncomfortable. Although there are safeguards in place to protect the privacy of your information as described below, there is also a risk that your information may be improperly disclosed.

### Authorization to Use and Disclose Protected Health Information

Before any health information about you may be shared as part of this study, the researchers are required to obtain your authorization. This section helps explain to you how your information will be used or shared with others involved in the study, and what protections will be in place to protect the privacy of your information.

Researchers and research staff at Michigan State University and Saginaw Valley State University Institutional Review Boards will use, share, and receive your information for this study. Your health information may also be shared with federal, state or local agencies that have oversight of the study or to whom access is required under the law. The information that is shared with those listed above may no longer be protected by federal privacy rules.

All of your information obtained for the study will be kept in a locked cabinet and/or a password protected computer in the study investigator's locked office. Your interview will be audio-recorded and transcribed.

Data from this study will be kept for at least three years after the project ends. All hard copies of notes and all audio recordings and transcripts will be destroyed as soon as allowable by law. Any identifying information like your name will be kept completely separate from the data, in a separate file. Your responses may be used in the write-up portion of the study, but results will be presented in the aggregate with no names or identifying information. From the interview, your words may be quoted without any name or identifying information attached. No information that could identify you in any way will be released to any individuals or agencies other than the research staff, unless required by law (this may include adult abuse shared during the optional in-person interview). Your choice to skip a question or to end participation will be kept confidential.

You have the right to refuse to sign this authorization. Your health care outside of the study, payment for your health care, and your health care benefits will not be affected if you choose not to sign this form. You will not be able to take part in this study if you do not sign this authorization.

If you do sign this authorization, it will not expire unless you change your mind and revoke it in writing. You may revoke this authorization at any time by sending a notice of revocation to the principal investigator as listed below.

### Your Rights to Participate, Say No, or Withdraw:

Participation is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. You may change your mind at any time and withdraw. You may choose not to answer specific questions or to stop participating at any time.

### **Costs and Compensation for Being in the Study:**

You will not be charged for any part of the study. You will receive a \$25 Visa gift card for your participation in the interview.

### **Conflict of Interest**

The research team has no conflicts of interest in this research study.

### **Contact Information:**

If you have any questions or concerns about the study, to report an injury, to revoke your authorization to use and disclose your information, or if you are interested in the findings from the study, you may contact the principal investigator: Amanda Woodward, 222 Baker Hall, 655 Auditorium Rd., East Lansing, MI 48824, 517-432-8702, awoodwar@msu.edu.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail <u>irb@msu.edu</u> or regular mail at 408 West Circle Drive, Olds Hall Room 207, MSU, East Lansing, MI 48824.

### **Documentation of Informed Consent:**

Your signature below means that you voluntarily agree to participate in this interview and that you authorize the use and disclosure of your protected health information as described above.

Signature

Date

You will be given a copy of this form to keep.

If I choose to participate in the optional in-person interview, I understand that my interview will be audiotaped.

Initial \_\_\_\_\_

### **Contact Information:**

If you have any questions or concerns about the study, to report an injury, to revoke your authorization to use and disclose your information, or if you are interested in the findings from the study, you may contact the principal investigator: Amanda Woodward, 222 Baker Hall, 655 Auditorium Rd., East Lansing, MI 48824, 517-432-8702, awoodwar@msu.edu.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail <u>irb@msu.edu</u> or regular mail at 408 West Circle Drive, Olds Hall Room 207, MSU, East Lansing, MI 48824.



Figure 4 – Montreal Cognitive Assessment (MOCA)

### **Recovery After Hospitalization – Interview Protocol**

Introduction: The purpose of this interview is to understand your experience recovering at home following hospitalization and how this period of time has affected your social relationships. By recovery, I mean getting better after having been in the hospital. By social relationships, I mean the family and friends you visit with and who may help with your recovery. In particular, I want to go back through the decision-making process you had when you were getting ready to leave the hospital.

Your answers will be used to better understand how decisions are made, how those decisions affect your recovery and how your social relationships impact your feelings. It also can help health care professionals like doctors, nurses and social workers support your recovery.

During the interview, you can share or not share anything you would like. Information from this interview may be published or presented at professional meetings; however, your name and identity will be kept confidential. Anything that could identify you will be deleted or changed.

Answering these questions is your choice. You can stop answering questions, not answer some questions or ask me to stop at any time. Participating or not participating in the interview will have no impact on your health care services.

I have a brief assessment and a consent form that I would like to read and have you sign before we begin. Please let me know if you have any questions.

**NOTE**: The Montreal Cognitive Assessment – Version 7 Original Version (Nasreddine et al., 2005) will be used to assess cognitive function. If the score is below 26, the interview will not continue. The participant will be thanked and the Visa gift card provided.

*Transition*: Okay, so let's move on to my first interview question. It is a general question just to get us started.

### Topic: Hospital discharge

**Question One:** Before you were here, you went to the hospital. Can you tell me a little bit about your hospital stay?

### **Possible Probes:**

- Why were you were hospitalized?
- How did you get to the hospital, through the ER, a scheduled visit?
- How long were you in the hospital?

**Questions Two:** Take a moment to think back to when you were getting ready to leave the hospital. Can you tell me what your discharge experience was like?

### **Possible Probes**:

- Where did you want to spend your recovery? What did anyone say to you about your preference? If so, how did you feel about the conversation? If not, how did that make you feel?
- What questions did you have about the process and your recovery? Were you able to ask those questions? How did you feel about those conversations?

### Topic: Expectations of social support.

**Question Three:** Continuing to think back to when you were in the hospital and getting ready for discharge. Can you tell me what expectations you had of who was going to help you during recovery?

### **Possible Probes:**

- What did you expect as far as the kind of social support you would receive?
- What amount of social support did you think you would have? How much support did you expect from family and friends?
- What expectations did you have of professional support?
- What was the difference, if there was one, between your expectations of support from family or friends and your expectations from professionals?
- What do you think of the idea that if someone had talked to you about your expectations, walked you through realistic scenarios of what might happen, that your expectations would have changed your decision making about where to recover?

*Transition:* Now we are going to move on to talk about how you are doing now. I want to talk about your current recovery and feelings about social support today.

### Topic: Current perception of social support

Question Four: Can you tell me what you think about the social support you have today?

### **Possible Probes:**

- Tell me about who visits you?
- How do you feel about the people that visit you?
- What kinds of visits do you have?
  - Probe for professional or personal visits, visitors are there to provide care or to give support
- What do you think about your current levels of social support?
- What would you think about having more or less support?
- How would you feel about having more support? less support?

### Topic: Difference between expectations and perception

**Question Five:** Remembering one of the things we talked about earlier, your expectations at discharge about social support. What is the difference between what you expected at discharge and what you are experiencing now as far as social support goes?

### **Possible Probes:**

- How does this difference, if there is one, make you feel?
  - *Probe for more detail. Even if the interviewee says the difference had no impact on them, probe for information about perceptions of the difference.*

**Question Six:** Have you shared all that you think is important about your discharge and recovery?

### **Possible Probes:**

What else would you like to tell me?

*Transition*: That is the end of the interview. I would like to thank you for your participation. I have the Visa gift card here in this envelope. The name and contact information of a person you can speak to if you have any questions later is also in the envelope. Thank you for your time and good luck with the rest of your recovery.

### Appendix 8 – Sample Field Notes

### Interview 017

Interviewee 017 was referred to me by the social worker at Nursing Home 1. I visited the facility at the time specified by the referral and asked Interviewee 17 if he would like to participate in the study. I knocked on the interviewee's room door and requested entry. Interviewee 017 invited me into the room. His bed was next to the window and furthest away from the door. He had medical equipment next to his bed and on a bedside table. He also had a large television, printer, and other electronic equipment on the desk, bedside table, over the bed table and on his bed. He was sitting in a chair next to his bed with a blanket over his lap. I introduced myself and reminded him of the conversation he had had with the social worker. I knelt down, in front of the chair and asked if he would like to participate in the interview. He said he would. I asked when would be convenient, he asked that I come back the next day and we agreed on 11am. He asked that I not wear any perfume or other strong odors as he was allergic. I left his room. Impression: As I entered the room, it seemed rather dim, the curtains were pulled across the window. While he had quite a bit of technology in the room, none of it was turned on. His roommate's television was turned on and the volume was audible from outside the room. The interviewee was a rather small man and had an oxygen tank next to the chair and a nasal cannula in use. He spoke quietly. I recognized the need to remind myself not to use shampoo or soap other than plain, non-perfumed. I also put a reminder in my calendar to make sure that I did not use perfume.

Interview: Before the interview today, when I walked outside (after being sure that I had not used any perfume or items with strong odors), I was concerned because my husband was smoking meat and it was strong smelling outside the house. I kept the windows open on my way to the interview. When I arrived at the interview, there was a smoke smell outside of the facility. I was concerned that the odor would be noticeable. I made sure to stop, when I entered the facility, and mindfully set aside my concerns in order to focus on the interview.

I arrived at the interviewee's room a few minutes early. I knocked on the door and requested entrance. He was sitting on the side of the bed and indicated that he remembered the scheduled interview. He asked that I sit in the chair next to him while he sat on the bed. I asked for permission to audio record and he agreed. I began the interview. A few times during the interview, Interviewee 017 excused himself to use the restroom. When he returned he had to rest for a few minutes before he could continue. His assessment and responses during the interview were indicative of loneliness. When asked the direct question about loneliness he said he was lonely. He had a lot to say about his use of technology.

Reflection: I was very moved by this interviewee. I had a hard time not recommending courses of action that would pair his technology skills with his social interaction. I did go so far as to say he might talk with the social worker in the facility about what he might be able to do for other residents with his skills. I have not experienced this level of concern with other interviewees and I need to be sure that I pay attention to these concerns in future interviews.

### Appendix 9 – Interviewer Reflection

As preparation for analysis of data collected through interviews, it is important to bracket my own experience and reflect on my beliefs, understanding of loneliness, experience with recovery settings, and thoughts about social support and discharge.

A reflection of my beliefs first makes me think about a process I have used in the past "this I believe." I have used this on many occasions to examine my thinking about various things. For example, I used it to produce a gift for my grandparents 60<sup>th</sup> wedding anniversary. I asked all of my family members to think about what values and beliefs were passed down to them from my grandparents. My reflection talked about how throwing a stone into water produces ripples that go on and on. I likened this to my influence on my children and how I need to think about what influence I will have beyond them. I used this process also when I wrote my personal statement and teaching philosophy. Thinking about belief now, in the context of research, makes me think about how my professional career has focused on older adults and the great respect I have for them. I know this bracketing process is supposed to help me set aside bias and prejudice. This is one belief I do not plan to set aside. I will treat all participants with respect.

I have learned a lot through the Comprehensive Examination and writing of the Literature Review for this dissertation. I have learned about loneliness and social support. I have experienced transient loneliness before. I often like to be alone and feel as though I don't need a lot of people around me. However, when I feel like others are not checking on me, when I am dealing with things that I could use help on, these are the times I feel lonely. I will try to set aside my own experiences of loneliness in order to better understand the experience of those I interview.

Social support is a concept I feel very knowledgeable about, from a personal standpoint. It has been difficult for me to accept the lack of family engagement, friend support, and professional interest in others throughout my life. This is because of my privilege in having much social support at all of these levels. To work with an older adult who has family who is not willing or interested in supporting their older adult family member has always been hard for me. I will have to be conscious of this when I am asking questions about social support from family, friends, and professionals.

Hospital discharge is a more fraught issue. My experience with hospital discharge planning both from a personal and professional aspect, has many negative connotations. I have not had many memorable good experiences with discharge and many have been very negative. I will need to work hard to set aside my preconceptions, particularly when it comes to analysis of the data, to ensure that I have not influenced the meaning I subscribe to other experience.

Finally, as a social worker who has worked in the nursing home and home care setting, I have a lot of lived experience of my own in these settings. I think my work as an ombudsman, someone who needed to be the voice for residents of long term care facilities will be helpful in setting aside biases in this project. As an ombudsman, I was often asked to voice a need of an older adult who couldn't or didn't want to speak for themselves. I had to advocate for things that I did not believe in or appreciate. That was my responsibility, as both an ombudsman and a social worker. Setting aside my own ideas about what "should" happen has gotten easier as I understand more of the roles and responsibilities of the social work profession. I will call on this experience as I engage in these interviews.

REFERENCES

### REFERENCES

- AARP. (2007). Women & long-term care. Washington, DC: AARP Public Policy Institute.
- AARP Public Policy Institute. (2009). *Chronic care: A call to action for health reform*. Washington, DC: AARP Public Policy Institute.
- Adler, N., & Stewart, J. (2007). *The MacArthur Scale of Subjective Social Status. MacArthur Research Network on SES & Health.* Retrieved from http://www.macses.ucsf.edu/research/psychosocial/subjective.php
- Administration on Aging. (2004). *Press release: AoA, NGA announce joint effort to help states strengthen long term care systems*. Retrieved from http://aoa.gov/AoARoot/ Press\_Room/For\_The\_Press/pr/archive/2004/May/05\_19\_04.aspx.
- Alpass, F.M., & Neville, S. (2003). Loneliness, health and depression in older males. *Aging & Mental Health*, 7(3), 212-216. DOI:10.1080/1360786031000101193.
- Alzheimer's Caregiver Support Act, S.311, 115<sup>th</sup> Congress (2017-2018).
- American Psychological Association. (2000). *Diagnostic and statistical manual of mental disorders (DSM-IV) (4th ed., text rev.)*. DOI:10.1176/appi.books.9780890423349.
- Andersson, L. (1985). Intervention against loneliness in a group of elderly women: An impact evaluation. *Social Science in Medicine*, 20(4), 355-364.
- Ayalon, L., & Shiovitz-Ezra, S. (2011). The relationship between loneliness and passive death wishes in the second half of life. *International Psychogeriatrics*, 23(10), 1677-1685. DOI:10.1017/S1041610211001384.
- Azeem, F., & Naz, M.A. (2015). Resilience, death anxiety, and depression among institutionalized and noninstitutionalized elderly. *Pakistan Journal of Psychological Research*, 30(1), 111-130.
- Baigi, A., Hildingh, C., Virdall, H., & Fridlund, B. (2008). Sense of coherence as well as social support and network as perceived by patients with a suspected or manifest myocardial infarction: A short-term follow up study. *Clinical Rehabilitation*, 22, 646-652.
- Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior*, *31*(2), 143-164. DOI:10.1177/1090198104263660.
- Baum, F. L. (1900). The wonderful Wizard of Oz. New York, NY: George M. Hill.
- Beal, C. (2006). Loneliness in older women: A review of the literature. Issues in Mental Health

Nursing, 27(7), 795-813. DOI:10.1080/01612840600781196.

- Becker, M. H. (1974). *The health belief model and personal health behavior*. Thorofare, N.J: Slack.
- Bell, R.A., & Gonzalez, M.C. (1988). Loneliness, negative life events, and the provisions of social relationships. *Communication Quarterly*, *36*(1), 1-15.
- Berg, S., Mellstrom, D., Persson, G., & Svanborg, A. (1981). Loneliness in the Swedish aged. *Journal of Gerontology*, *36*(3), 342-349.
- Bergland, A., & Kirkevold, M. (2006). Thriving in nursing homes in Norway: Contributing aspects described by residents. *International Journal of Nursing Studies*, 43, 681-691.
- Bondevik, M., & Skogstad, A. (1998). The oldest old, ADL, social network, and loneliness. *Western Journal of Nursing Research*, 20(3), 325+.
- Bonifas, R.P., Simons, K., Biel, B., & Kramer, C. (2014). Aging and place in long-term care settings: Influences on social relationships. *Journal of Aging and Health*, 26(8), 1320-1339. DOI:10.1177/0898264314535632.
- Brown, J.G. (1997). *Medicare hospital discharge planning*. Washington, DC: United States Department of Health and Human Services.
- Bryan, J.L., Baker, Z.G., & Tou, R.Y.W. (2015). Prevent the blue, be true to you: Authenticity buffers the negative impact of loneliness on alcohol-related problems, physical symptoms and depressive and anxiety symptoms. *Journal of Health Psychology*, 1-12. DOI:10.1177/1359105315609090.
- Buring, S.M., Bhushan, A., Broeseker, A., Conway, S., Duncan-Hewitt, W., Hansen, L., & Westberg, S. (2009). American Journal of Pharmacological Education, 73(4), 59.
- Bylund, C.L., Galvin, K.M., Dunet, D.O., & Reyes, M. (2011). Using the extended Health Belief Model to understand siblings' perceptions of risk for hereditary hemochromatosis. *Patient Education and Counseling*, 82, 36-41. DOI:10.1016/j.pec.2010.03.009
- Cacioppo, J.T., Ernst, J.M., Burleson, M.H., McClintock, M.K., Malarkey, W.B., Hawkley, L.C., ... Berntson, G.G. (2000). Lonely traits and concomitant physiological processes: The MacArthur social neuroscience studies. *International Journal of Psychophysiology*, 35, 143-154.
- Cacioppo, S., Grippo, A.J., London, S., Goossens, L., & Cacioppo, J.T. (2015). Loneliness: Clinical import and interventions. *Perspectives on Psychological Science*, 10(2), 238-249. DOI:10.1177/1745691615570616.

Cacioppo, J.T., Hawkley, L.C., & Thisted, R.A. (2010). Perceived social isolation makes me
sad: 5-year cross-lagged analyses of loneliness and depressive symptomatology in the Chicago Health, Aging, and Social Relations study. *Psychology and Aging*, 25(2), 453-463. DOI:10.1037A0017216.

- Cacioppo, J.T., Hughes, M.E., Waite, L.J., Hawkley, L.C., & Thisted, R.A. (2006). Loneliness as a specific risk factor for depressive symptoms: Cross-sectional and longitudinal analyses. *Psychology and Aging*, *21*(1), 140-151. DOI:10.1037/0882.7974.21.1.140.
- Cacioppo, J.T., & Patrick, W. (2008). *Loneliness: Human nature and the need for social connection.* New York, NY: W.W. Norton & Company.
- Callary, B., Rathwell, S., Young, B.W. (2015). Insights on the process of using Interpretive Phenomenological Analysis in a sport coaching research project. *The Qualitative Report*, 20(2), 63-75.
- Calvillo-King, L., Arnold, D., Eubank, K.J., Lo, M., Yunyongying, Pl, Stieglitz, H., & Halm, E.A. (2012). Impact of social factors on risk of readmission or mortality in pneumonia and hearth failure: A systematic review. *Journal of General Internal Medicine*, 28(2), 269-282. DOI:10.1007/s11606-012-2235-x
- Campaign to End Loneliness. (2011). *Measuring your impact on loneliness in later life*. London, England: Campaign to End Loneliness.
- Cantril, H. (1965). *The pattern of human concerns*. New Brunswick, NJ: Rutgers University Press.
- Caregiver Program Information Dissemination Act of 2017, S.165, 115<sup>th</sup> Congress (2017-2018).
- Centers for Disease Control and Prevention (CDC). (2013). *Health places terminology: Aging in place*. Atlanta, GA: Centers for Disease Control and Prevention. Retrieved from http://www.cdc.gov/healthyplaces/terminology.htm.
- Centers for Medicare & Medicaid. (2016). *Readmissions Reduction Program (HRRP)*. Retrieved from https://www.cms.gov/medicare/medicare-fee-for-servicepayment/acuteinpatientpps/readmissions-reduction-program.html.
- Chan, N., Anstey, K.J., Windsor, T.D., & Luszcz, M.A. (2011). Disability and depressive symptoms in later life: The stress-buffering role of informal and formal support. *Gerontology*, 57, 180-189. DOI:10.1159/000314158.
- Chen, B., Covinsky, K.E., Cenzer, I.S., Adlwer, N., & Williams, B.A. (2012). Subjective social status and functional decline in older adults. *Journal of General Internal Medicine*, 27(6), 693-699. DOI:10.1007/s11606-011-1963-7.
- Chronister, J.A. (2009). Chapter 6: Social support and rehabilitation: Theory, research and measurement. In E.D.S. Cardoso, & J.A. Chronister (Eds). *Psychosocial Adjustment to*

Chronic Illness and Disability: A Handbook for Evidence-Based Practitioners in Rehabilitation. New York, NY: Springer Publishing Company, LLC.

- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: An Interpretative Phenomenological Analysis. *The Gerontologist*, 48(6), 711-720.
- Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, *38*(5), 300-314.
- Cohen, S. (2004). Social relationships and health. American Psychologist, 59, 676-684.
- Cohen, S., & Willis, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310-357. DOI:003-2909/85.
- Cohen-Mansfield, J., Hazan, H., Lerman, Y., & Shalom, V. (2016). Correlates and predictors of loneliness in older-adults: a review of quantitative results informed by qualitative insights. *International Psychogeriatrics*, 28(4), 557-576. DOI:10.1017/S1041610215001532.
- Comijs, H.C., Penninx, B.W.J.H., Knipscheer, K.P.M., & Van Tilburg, W. (1999).
  Psychological distress in victims of elder mistreatment: The effects of social support and coping. *Journal of Gerontology: Psychological Sciences*, 54 (4), P240-P245.
- Cornwell, E.Y., & Waite, L.J. (2009). Social disconnectedness, perceived isolation, and health among older adults. *Journal of Health and Social Behavior*, 50, 31-48.
- CSWE (Council on Social Work Education). (2015). *Educational policy and accreditation* standards for Baccalaureate and Master's social work program. Alexandria, VA: Council on Social Work Education.
- Cummins, R.C. (1988). Perceptions of social support, receipt of supportive behaviors, and locus of control as moderators of the effects of chronic stress. *Journal of Community Psychology*, *16*(5), 685-700.
- Cutchin, M.P. (2003). The process of mediated aging-in-place: A theoretically and empirically based model. *Social Science and Medicine*, *57*, 1077-1090. DOI:10.1016/S0277-9536(02)00486-0.
- Dalal, H.M., Zawada, A., Jolly, D., Moxham, T., & Taylor, R.S. (2010). Home based versus centre based cardiac rehabilitation: Cochrane systematic review and meta-analysis. *British Medical Journal*, 19(340), b5631. DOI:10.1136/bmj.b5631.
- de Jong Gierveld, J., & Fokkema, T. (2015). Strategies to prevent loneliness. In A. Sha'ked, & A. Rokach (Eds.), *Addressing loneliness: Coping, prevention and clinical interventions* (218-230, Chapter 14). New York, NY: Routledge/Taylor & Francis Group.

- de Jong Gierveld, J., & Kamphuis, F.H. (1985). The development of a Rasch-type loneliness scale. *Applied Psychological Measurement*, *9*, 289-299.
- de Jong Gierveld, J., & Van Tilburg, T. (2006). A 6-item scale for overall, emotional, and social loneliness: Confirmatory tests on survey data. *Research on Aging*, *28*(5), 582-598. DOI:10.1177/0164027506289723
- Department of Licensing and Regulatory Affairs (LARA). (2016). *Bureau of community and health systems*. Retrieved from http://www.michigan.gov/lara/0,4601,7-154-63294---,00.html.
- Donaldson, J.M., & Watson, R. (1996). Loneliness in elderly people: An important area for nursing research. *Journal of Advanced Nursing*, 24, 952-959. DOI: 10.1111/j.1365-2648.1996.tb02931.x
- Dong, X., Beck, T., & Simon, M.A. (2009). Loneliness and mistreatment of older Chinese women: Does social support matter? *Journal of Women & Aging*, 21(4), 293-302. DOI:10.1080/08952840903285252.
- Drageset, J., Espehaug, B., & Kirkevold, M. (2011). The impact of depression and sense of coherence on emotional and social loneliness among nursing home resident without cognitive impairment – a questionnaire survey. *Journal of Clinical Nursing*, 21, 965-974. DOI:10.111/j.1365-2702.2011.03932.x.
- Ebesutani, C., Drescher, C.F., Reise, S.P., Heiden, L., Hight, T.L., Damon, J.D., & Young, J. (2012). The importance of modeling method effects: Resolving the (uni)dimensionality of the loneliness questionnaire. *Journal of Personality Assessment*, 94(2), 186-195. DOI:10.1080/00223891.2011.627967.
- Eng, P.M., Rimm, E.B., Fitzmaurice, G., & Kawachi, I. (2002). Social ties and change in social ties in relation to subsequent total and cause-specific mortality and coronary heart disease incidence in men. *American Journal of Epidemiology*, *155*, 700-709.
- Eshbaugh, E.M. (2009). The role of friends in predicting loneliness among older women living alone. *Journal of Gerontological Nursing*, 35(5), 13-16.
- Foss, C., & Hofoss, D. (2011). Elderly persons' experiences of participation in hospital discharge process. *Patient Education and Counseling*, 85, 68-73. DOI:10.1016/j.pec.2010.08.025.
- Frakt, A. (January 4, 2016). *The hidden financial incentives behind your shorter hospital stay*. New York, NY: The New York Times
- Freud, S. (1920). *Introductory lectures on psycho-analysis*. New York, NY: W.W. Norton & Company.

Fromm-Reichmann, F. (1959). Loneliness. Psychiatry, 22(1), 1-15.

- Gero, G. (1936). The construction of depression. *The International Journal of Psycho-Analysis*, 17, 423-461.
- Gerst-Emerson, K., & Jayawardhana, J. (2015). Loneliness as a public health issue: The impact of loneliness on health care utilization among older adults. *American Journal of Public Health*, *105*(5), 1013-1019. DOI:10.2105/AJPH.2014.302427.
- Gerst-Emerson, K., Shovali, T.E., & Markides, K.S. (2014). Loneliness among very old Mexican Americans: Findings from the Hispanic established populations epidemiologic studies of the elderly. *Archives of Gerontology and Geriatrics*, 59(1), 145-149.
- Gochman, D.S. (1997). Health Behavior Research: definitions and Diversity. In Handbook of Health Behavior Research I: Personal and Social Determinants. Gochman, David S. (Ed.). New York, NY: Plenum Press.
- Gold, J. G., & Kaufman, S. M. (1970). Development of care of elderly: Tracing the history of institutional facilities. *The Gerontologist*, 10, 262–274. DOI:10.1093/geront/10.4Part1.262.
- Gottlieb, B.H. (1978). The development and application of a classification scheme of informal helping behaviors. *Canadian Journal of Behavioral Sciences*, *10*(2), 105-115.
- Greaves, C.J., & Farbus, L. (2006). Effects of creative and social activity on the health and wellbeing of socially isolated older people: Outcomes from a multi-method observational study. *The Journal of the Royal Society for the Promotion of Health*, 126(3), 134-142. DOI:10.1177/1466424006064303.
- Greer, I.M. (1953). Roots of loneliness: Loneliness is living in a shell of unfulfilled longings for support, communication, and sharing. *Pastoral Psychology, June*, 27-31.
- Greer, S.A., Nwaise, I.A., & Casper, M.L. (2010). *Atlas of heart disease hospitalizations among Medicare beneficiaries*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.
- Grenade, L., & Boldy, D. (2008). Social isolation and loneliness among older people: Issues and future challenges in community and residential settings. *Australian Health Review*, 32(3), 468-478.
- Hand, C., McColl, M.A., Birtwhistle, R., Kotecha, J.A., Batchelor, D., & Barber, K.H. (2014). Social isolation in older adults who are frequent users of primary care services. *Canadian Family Physician*, 60, e322-e329.

Harris-Kojetin, L., Sengupta, M., Park-Lee, E., et al. (2016). Long-term care providers and

services users in the United States: Data from the National Study of Long-Term Care Providers, 2013-2014. National Center for Health Statistics. *Vital Health Statistics, 3*(38).

- Harrison, J.A., Mullen, P.D., & Green, L.W. (1992). A meta-analysis of studies of the Health Belief Model with adults. *Health Education Research: Theory & Practice*, 7(1), 107-116. DOI:10.1093/her/7.1.107.
- Hawkley, L. C., Burleson, M. H., Berntson, G. G., & Cacioppo, J. T. (2003). Loneliness in everyday life: Cardiovascular activity, psychosocial context, and health behaviors. *Journal of Personality and Social Psychology*, 85, 105–120. DOI:10.1037/0022-3514.85.1.105.
- Hawkley, L.C., & Cacioppo, J.T. (2003). Loneliness and pathways to disease. *Brain, Behavior, and Immunity*, 17, S98-S105. DOI:10.1016/S0889-1591(02)00073-9.
- Hawkley, L.C., & Cacioppo, J.T. (2010). Loneliness matters: A theoretical and empirical review of consequences and mechanisms. *Annuals of Behavioral Medicine*, 40(2), 1-14. DOI:10.1007/s12160-010-9210-8.
- Hawkley, L.C., Masi, C.M., Berry, J.D., & Cacioppo, J.T. (2006). Loneliness is a unique predictor of age-related differences in systolic blood pressure. *Psychology and Aging*, 21(1), 152-164. DOI:10.1037/0882-7974.21.1.152.
- Hawthorne, G. (2006). Measuring social isolation in older adults: Development and initial validation of the friendship scale. *Social Indicators Research*, 77, 512-548. DOI:10.1007/s11205-005-7746-y.
- Hayden, J.A. (2014). *Introduction to Health Behavior Theory, 2nd edition*. Burlington, MA: Jones & Bartlett.
- Health and Retirement Study. (2008). Design history. Retrieved from https://hrs.isr.umich.edu/sites/default/files/biblio/DesignHistory.pdf
- Health and Retirement Study, Waves 2008 2014 public use dataset. (2014). Produced and distributed by the University of Michigan with funding from the National Institute on aging (grant number NIA U02AG009740). Ann Arbor, MI, (2014).
- Healthcare Cost and Utilization Project (HCUP). (2010a). *Cost by age: facts and figures: Statistics on hospital-based care in the United States, 2009.* Rockville, MD: U.S. Agency for Healthcare Research and Quality.
- Healthcare Cost and Utilization Project (HCUP). (2010b). Discharge status: HCUP facts and figures: Statistics on hospital-based care in the United States, 2009. Rockville, MD: U.S. Agency for Healthcare Research and Quality.

Heffner, K.L., Waring, M.E., Roberts, M.B., Eaton, C.B., & Gramling, R. (2011). Social

isolation, C-reactive protein, and coronary heart disease mortality among communitydwelling adults. *Social Science & Medicine*, 72, 1482-1488. DOI:10.1016/j.socscimed.2011.03.016.

- Heikkinen, R.-L., & Kauppinen, M. (2011). Mental well-being: A 16-year follow-up among older residents in Jyvaskyla. Archives of Gerontology and Geriatrics, 52, 33-39. DOI:10.1016/jarchger.2010.01.017.
- Heinrich, L.M., & Gullone, E. (2006). The clinical significance of loneliness: A literature review. *Clinical Psychology Review*, 26, 695-718. DOI:10.1016/j.cpr.2006.04.002.
- Herlitz, J., Wiklund, I., Caidahl, K., Hartford, M., Haglid, M., Karlsson, B., Sjoland, H., & Karlsson, T. (1998). The feeling of loneliness prior to coronary artery bypass grafting might be a predictor of short- and long-term postoperative mortality. *European Journal* of Vascular and Endovascular Surgery, 16, 120-125.
- Hines, A.L., Barrett, M.L., Jiang, J., Steiner, C.A. (2014). Conditions with the largest number of adult hospital readmissions by payer, 2011. *Statistical Brief #172*. Healthcare Cost and Utilization Project.
- Hochbaum, G.M. (1958). *Public participation in medical screening programs: A sociopsychological study* (Public Health Service Publication No. 572). Washington, DC: Government Printing Office
- Holmen, K., Ericsson, K., Andersson, L., & Winblad, B. (1992). Loneliness among elderly people living in Stockholm: A population study. *Journal of Advanced Nursing*, 17, 14-51.
- Holt-Lunstad, J., Smith, T.B., Baker, M., Harris, T., & Stephenson, D. (2015). Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspectives on Psychological Science*, 10(2), 227-237. DOI:10.117/1745691614568352.
- Holt-Lunstad, J., Smith, T.B., & Layton, J.B. (2010). Social relationships and mortality risk: A meta-analytic review. *PLoS Medicine*, 7(7), e1000316. DOI:10.1371/journal.pmed.1000316.
- Hooyman, N. R. (2015). Social and health disparities in aging: Gender inequities in long-term care." *Generations* 38.4 (2015): 25-32
- House, J.S., Landis, K.R., & Umberson, D. (1988). Social relationships and health. *Science*, 24(1), 540+.
- Howard, A.F., Goddard, K., de Bibiana, R.T., Pritchard, S., Olson, R., & Kazanjian, A. (2016). Adult childhood cancer survivors' narratives of managing their health: The unexpected and the unresolved. *Journal of Cancer Survivors*, 10, 711-725. DOI:10.1007x11764-016-0517-8.

- Huber, D.L., & McClelland, E. (2003). Patient preferences and discharge planning transitions. *Journal of Professional Nursing*, 19(3), 204-210. DOI:10.1016/S8755-7223(03)00071-7.
- Hughes, M.E., Waite, L.J., Hawkley, L.C., & Cacioppo, J.T. (2004). A short scale for measuring loneliness in large surveys: Results from two population-based studies. *Research on Aging*, 26(6), 655-672. DOI:10.1177/0164027504268574.
- Hurley, A.C., & Volicer, L. (2002). Alzheimer disease "It's Okay, Mama, If You Want to Go, It's Okay". *Journal of the American Medical Association*, 288(18), 2324-2331. DOI:10.1001/jama.288.18.2624.
- Hutchinson, A., Graco, M., Rasekaba, T.M., Parikh, S., Berlowitz, D.J., & Lim, W.K. (2015). Relationship between health-related quality of life, comorbidities, and acute health care utilisation, in adults with chronic conditions. *Health and Quality of Life Outcomes*, 13, 69--79. DOI:10.1186/s12955-015-0260-2.
- Janz, N. K., & Becker, M. H. (1984). The health belief model: A decade later. *Health Education Quarterly*, 11, 1-47.DOI:10.1177\_1090198184011.00101.
- Jaremka, L.M., Andridge, R.R., Fagundes, C.P., Alfano, C.M., Povoski, S.P., Lipari, A.M., ... Kiecolt-Glaser, J.K. (2014). Pain, depression, and fatigue: Loneliness as a longitudinal risk factor. *Health Psychology*, 33(9), 948-957. DOI:10.1037/a0034012.
- Jopling, K. (2015, January). *Promising approach to reducing loneliness and isolation in later life*. Campaign to End Loneliness: Connections in Older Age. London, England: AgeUK.
- Jurkowski, E. (2004). Promoting the mental health of older adults in an aging society: The consumer's perspective. *The Gerontologist*, 44(1), 496.
- Juster, F.T., & Suzman, R. (1995). An overview of the health and retirement study. *The Journal* of Human Resources, 30, S7-S56. DOI:edsjsr.10.2307.146277.
- Kim, J.E., & Zane, N. (2016). Help-seeking intentions among Asian American and White American students in psychological distress: Application of the Health Belief Model. *Cultural Diversity and Ethics Minority Psychology*, 22(3), 311-321. DOI:10.1037/cdp00000056.
- Klein, M. (1963). On the sense of loneliness. Writings of Melanie Klein. 1946-1963. New York: The New Library of Psychoanalysis, pp.300-313.
- Klug, G., Lacruz, M.E., Emeny, R.T., Hafner, S., Ladwig, K., & Huber, D. (2014). Aging without depression: A cross-sectional study. *Psychodynamic Psychiatry*, 42(1), 5-22.

Kochanek, K.D., Murphy, S.L., Xu, J., & Tajada-Vera, B. (2017). Death: Final data for 2014.

National Vital Statistics Report, 65(4).

- Kwon, H.J., Ahn, M., Lee, S., & Kim, S. (2015). U.S. baby boomers' desire to age in place and residential satisfaction. *Journal of Housing for the Elderly*, 29(4), 348-372. DOI:10.1080/02763893.2015.1055028.
- Leon-Perez, G., Wallston, K.A., Goggins, K.M., Poppendeck, H.M., & Kripalani, S. (2016). Effects of stress, health competence, and social support on depressive symptoms after cardiac hospitalization. *Journal of Behavioral Medicine*, 39, 441-452. DOI:10.1007/x10865-015-9702-x
- Lett, H.S., Blumenthal, J.A., Babyak, M.A., Strauman, T.J., Robins, C., & Sherwood, A. (2005). Social support and coronary heart disease: Epidemiologic evidence and implications for treatment. *Psychosomatic Medicine*, 67, 869-878. DOI:10.1097/01.psy.0000188393.7357.0a.
- Litty, C.G., Kowalski, R., & Minor, S. (1996). Moderating effects of physical abuse and perceived social support on the potential to abuse. *Child Abuse & Neglect*, 20(4), 305-314.
- Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J.C., & Stuck, A.E. (2006). Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *The Gerontologist*, 46(4), 503-513.
- Lubben, J., & Gironda, M. (2004). Measuring social networks and assessing their benefits. In C. Phillipson, G. Allan, & D. Morgan (Eds.), *Social Networks and Social Exclusion: Sociological and Policy Perspectives* (pp. 20-35). Hampshire, England: Ashgate Publishing.
- Luhmann, M., & Hawkley, L.C. (2016). Age differences in loneliness from late adolescence to oldest old age. *Developmental Psychology*, 52(6), 943-959. DOI:10.1037/dev0000117.
- Luo, Y., Hawkley, L.C., Waite, L.J., & Cacioppo, J.T. (2012). Loneliness, health, and mortality in old age: A national longitudinal study. *Social Science Medicine*, 74(6), 907-914. DOI:10.1016/j.socscimed.2011.11.028.
- Luo, Y., & Waite, L.J. (2014). Loneliness and mortality among older adults in China. Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 69(4), 63-645. DOI:10.1093/geronb/gbu007.
- Magilvy, J.K., & Congdon, J.G. (2000). The crisis nature of health care transitions for rural older adults. *Public Health Nursing*, *17*(5), 336-345.
- Mankowski, E. S., & Wyer, R. S. J. (1997). Cognitive causes and consequences of perceived social support. In G. R. Pierce, B. Lakey, I. G. Sarason, & B. G. Sarason (Eds.),

Sourcebook of social support and personality (pp. 141-165). New York: Plenum Press.

- Mann, F., Bone, J.K., Lloyd-Evans, B., Frerichs, J. Pinfold, V., Ma, R., Wang, J., & Johnson, S. (2017) A life less lonely: The state of the art in interventions to reduce loneliness in people with mental health problems. *Social Psychiatry and Psychiatric Epidemiology*, 52(6), 627-638. DOI:10.1007/s00127-017-1392-y.
- Masi, C.M., Chen, H.Y., Hawkley, L.C., & Cacioppo, J.T. (2011). A meta-analysis of interventions to reduce loneliness. *Perspectives is Social Psychology Review*, 15(3), 219-266. DOI:10.1177/1088868310377394.
- Masterson, A. (2017, June 23). *Loneliness, what it is, how it makes you sick, and how to cure it.* The Age: Victoria News. Retrieved from: http://www.theage.com.au/victoria/lonelinesswhat-it-is-how-it-makes-you-sick-and-how-to-cure-it-20170621-gwvikj.html
- Medicare and Medicaid Program: Conditions of participation for home health agencies, 82 FR 4504 (July 13, 2017) (to be codified at 42 C.F.R. pt. 409, 410, 418, 440, 484, 485, 488).
- Michigan Social Work Continuing Education Collaborative. (2017). Michigan Social Work Collaborative Course Listing. Retrieved October 20, 2017 from https://www.socialworkcec.com/how-to-view-course-listings.
- Missotten, P., Thomas, P., Squelard, G., Di Notte, D., Fontaine, O., Paquay, L., ... & Ylieff, M. (2009). Impact of place of residence on relationship between quality of life and cognitive decline in dementia. *Alzheimer Disease Association Disorders*, 23(4), 395-400.
- Mo, P.K.K, Chong, E.S.K., Mak, W.W.S., Wong, S.Y.S., & Lau, J.T.F. (2016). Physical activity in people with mental illness in Hong Kong: Application of the Health Belief Model. *Journal of Sport & Exercise Psychology*, *38*, 203-208. DOI:10.1123/jsep.2015-0061.
- Molineux, M. (2017). *Definition of social support*. A Dictionary of Occupational Science and Occupational Therapy. Oxford University Press
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage Publications, Inc.
- Musich, S., Wang, S.S., Hawkins, K., & Yeh, C.S. (2015). The impact of loneliness on quality of life and patient satisfaction among older, sicker adults. *Gerontology & Geriatric Medicine, January - December*, 1-9. DOI:10.1177/2333721415582119.
- National Forum on Education Statistics. (2015). *Forum guide to alternative measures of socioeconomic status in education data systems*. (NFES 2015-158). U.S. Department of Education. Washington, DC: National Center for Education Statistics.
- Nausheen, B., Gidron, Y., Gregg, A., Tissarchondou, H.S., & Peveler, R. (2007). Loneliness, social support and cardiovascular reactivity to laboratory stress. *Stress*, *10*(1), 37-44.

DOI:10.1080/10253890601135434.

- Nicolaisen, M., & Thorsen, K. (2014). Who are lonely? Loneliness in different age groups (18-81 years old), using two measures of loneliness. *International Journal of Aging and Human Development*, 78(3), 229-257. DOI:10.2196/AG.78.3.b.
- Nikmat, A.W., Al-Mashoor, A.H., & Hashim, N.A. (2015). Quality of life in people with cognitive impairment: Nursing homes versus home care. *International Psychogeriatrics*, 27(5), 815-824. DOI:10.1017/S1041610214002609.
- Nikmat, A.W., Hawthorne, G., & Al-Mashoor, S.H. (2015). The comparison of quality of life among people with mild dementia in nursing home and home care preliminary report. *Dementia*, *14*(1), 114-125. DOI:10.1177/1471301213494509.
- Office of Disease Prevention and Health Promotion. (2017). *Health-related quality of life and well-being*. Retrieved from https://www.healthypeople.gov/2020/about/foundation-health-measures/Health-Related-Quality-of-Life-and-Well-Being.
- Ortman, J.M., Velkoff, V.A., & Hogan, H. (2014). *An aging nation: The older population in the United States*. Washington, DC: U.S. Department of Commerce.
- Padgett, D.K. (2008). *Qualitative methods in social work research*, 2<sup>nd</sup> edition. Thousand Oaks, CA: Sage Publications, Inc.
- Paul, C., Ayis, S., & Ebrahim, S. (2006). Psychological distress, loneliness and disability in old age. *Psychology, Health & Medicine*, 11(2), 221-232. DOI:10.1080/13548500500262945.
- Penning, M.J., Liu, G., & Chou, P.H.B. (2014). Measuring loneliness among middle-aged and older adults: The UCLA and de Jong Gierveld loneliness scales. *Social Indicators Research*, 118, 1147-1166. DOI:10.1007/s11205-013-0461-1.
- Peplau, H.E. (1955). Loneliness. The American Journal of Nursing, 55(12), 1476-1481.
- Peplau, L.A., & Perlman, D. (Eds.). (1982). Chapter 1: Perspectives on loneliness. In Loneliness: A sourcebook of current theory, research and therapy. pp. 1-20. New York, NY: John Wiley & Sons.
- Perlman, D., & Peplau, L.A. (1984). Chapter 2: Loneliness research: A survey of empirical findings. In L.A. Peplau & S. Goldston (Eds.). *Preventing the harmful consequences of severe and persistent loneliness*. (pp. 13-46). U.S. Government Printing Office, 1984. DDH Publication No. (ADM) 84-1312.
- Pettigrew, S., & Roberts, M. (2008). Addressing loneliness in later life. *Aging & Mental Health*, 12(3), 302-309.

- Pikhartova, J., Bowling, A., & Victor, C. (2016). Is loneliness in later life a self-fulfilling prophecy? Aging & Mental Health, 20(5), 549-549. DOI:10.1080/13607863.2015.1023767.
- Pinquart, M., & Sorensen, S. (2001). Influences on loneliness in older adults: A meta-analysis. Basic and Applied Social Psychology, 23(4), 245-266. DOI:10.1207/S15324834BASP2304-2.
- Popejoy, L.L., Galambos, C., & Madsen, R. (2012). Challenges to hospital discharge planning for older adults. *Clinical Nursing Research*, 21(4), 431-449. DOI:10.1177/1054773812436373.
- Popejoy, L.L., Moylan, K., & Galambos, C. (2009). A review of discharge planning research of older adults 1990-2008. Western Journal of Nursing Research, 31(7), 923-947. DOI:10.1177/0193945909334855.
- Popejoy, L.L., Stetzer, F., Hicks, L., Rantz, M.J., Calambos, C., Popescu, M., Khalilia, M.A., Marek, K.D. (2015). Comparing aging in place to home care: Impact of nurse care coordination on utilization and costs. *Nursing Economics*, 33(6), 306-313.
- Procidano, M. E., & Smith, W. W. (1997). Assessing perceived social support: The importance of context. In G. R. Pierce, B. Lakey, I. G. Sarason, & B. R. Sarason (Eds.), *Sourcebook* of social support and personality (pp. 93–106). New York, NY: Plenum Press.
- Qian, X., Russell, L.B., Valiyeva, E., Miller, J.E. (2010). 'Quicker and sicker' under Medicare's prospective payment system for hospitals: New evidence on an old issue from a national longitudinal survey. *Bulletin of Economic Research*, 63(1), 3307-3378. DOI:10.1111/j.1467-8586.2010.00368x.
- Rees, C.A., Karter, A.J., & Young, B.A. (2010). Race/Ethnicity, social support, and associations with diabetes self-care and clinical outcomes in NHANES. *Diabetes Education*, 36(3), 435-445. DOI:10.1177/0145721710364419.
- Rico-Uribe, L.A., Caballero, F.F., Olaya, B., Tobiasz-Adamczyk, B., Koskinen, S., Leonardi, M., ... Miret, M. (2016). Loneliness, social networks and health: A cross-sectional study in three countries. *PLoS ONE*, 11(1), e0145264. DOI:10.1371/journal.pone.0145264.
- Rook, K.S., & Dooley, D. (1985). Applying social support research: Theoretical problems and future directions. *Journal of Social Issues*, *41*(1), 5-28.
- Rosenstock, I.M., Strecher, V.J., Becker, M.H. (1988). Social learning theory and the Health Belief Model. *Health Education Quarterly*, 15(2), 175-183.
- Russell, D., Peplau, L.A., & Cutrona, C.E. (1980). The Revised UCLA Loneliness Scale: Concurrent and discriminant validity evidence. *Journal of Personality and Social Psychology*, 39(3), 472-480.

- Russell, D., Cutrona, C.E., Rose, J., & Yurko, K. (1984). Social and emotional loneliness: An examination of Weiss's typology of loneliness. *Journal of Personality and Social Psychology*, 46(6), 1313-1321.
- Russell, D.W., Cutrona, C.E., & Wallace, R.B. (1997). Loneliness and nursing home admission among rural older adults. *Psychology and Aging*, *17*(4), 574-589.
- Saunders, G.H., Frederick, M.T., Silverman, S., & Papesh, M. (2013). Application of the health belief model: Development of the hearing beliefs questionnaire (HBQ) and its associations with hearing health behaviors. *International Journal of Audiology*, 52(8), 558-567. DOI:10.3109/14992027.2013.791030
- Schoenmakers, E.C., Van Tilburg, T.G., & Fokkema, T. (2014). Awareness of risk factors for loneliness among third agers. *Ageing & Society*, 34, 1035-1051. DOI:10.1017/S0144686X12001419.
- Shaw, J.G., Farid, M., Noel-Miller, C., Joseph, N., Houser, A., Asch, S.M., Bhattacharya, J., & Flowers, L. (2017). Social isolation and Medicare spending: Among older adults, objective isolation increases expenditures while loneliness does not. *Journal of Aging and Health*, 29(7), 1119-1143. DOI:10.117/0898264317703559.
- Shiovitz-Ezra, S., & Ayalon, L. (2012). Use of direct versus indirect approaches to measure loneliness in later life. *Research on Aging*, 34(5), 572-591. DOI:10.1177/0164027511423258.
- Simon, M.A., Chang, E.-S., Zhang, M., Ruan, J., & Dong, X. (2014). The prevalence of loneliness among U.S. Chinese older adults. *Journal of Aging and Health*, 26(7), 1172-1188. DOI:10.1177/0898264314533722.
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1*, 39-54.
- Smith, J.A., Flowers, P., & Larkin, M. (2013). *Interpretative Phenomenological Analysis: Theory, method and research*. Los Angeles, CA: Sage.
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (2nd ed., pp. 53-80). London, UK: Sage.
- Steptoe, A., Owen, N., Kunz-Ebrecht, S.R., & Brydon, L. (2004). Loneliness and neuroendocrine, cardiovascular, and inflammatory stress responses in middle-aged men and women. *Psychoneuroendocrinology*, 29, 593-611. DOI:10.1016/S0306-4530(03)00086-6.

- Stokes, J.E. (2016). Marital quality and loneliness in later life: A dyadic analysis of older married couples in Ireland. *Journal of Social and Personal Relationships*, 1-22. DOI:10.1177/0265407515626309.
- Stretcher, V.J.; Champion, V.L.; Rosenstock, I.M. (1997). The health belief model and health behavior. In D.S. Gochman (Ed.), *Handbook of health behavior research*. Vol. 1 (71-91). New York, NY: Plenum.
- Szanton, S. L., Wolff, J. L., Leff, B., Roberts, L., Thorpe, R. J., Tanner, E. K., Boyd, C.M., Xue, Q.-L., Guralnik, J., Bishai, D., & Gitlin, L. N. (2015). Preliminary data from community aging in place, advancing better living for elders, a patient-directed, team-based intervention to improve physical function and decrease nursing home utilization: The first 100 individuals to complete a Centers for Medicare and Medicaid services innovation project. *Journal of the American Geriatrics Society*, 63(2), 371-374. DOI:10.1111/jgs.13245.
- te Boekhorst, S., Depla, M.F.I.A., de Lange, J., Pott, A.M., & Eefsting, J.A. (2009). The effects of group living homes on older people with dementia: A comparison with traditional nursing home care. *International Journal of Geriatric Psychiatry*, 24, 970-978. DOI:10.1002/gps.2205.
- Theeke, L.A. (2009). Predictors of loneliness in U.S. adults over age sixty-five. Archives of *Psychiatric Nursing*, 23(5). 387-369. DOI:10.1016/j.apnu.2008.11.002.
- Theeke, L.A. (2014). Older people who report loneliness have increased risk of mortality and functional decline. *Evidence Based Nursing*, *16*(3), 95-96. DOI:10.1136/eb-2012-101052.
- Theeke, L.A., & Mallow, J. (2013). Loneliness and quality of life in chronically ill rural older adults. *The American Journal of Nursing*, *113*(9), 28-37.
- Thoits, P.A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behavior*, *35*, 53-79.
- Thurston, R.C., & Kubzansky, L.D. (2009). Women, loneliness, and incident coronary heart disease. *Psychosomatic Medicine*, *71*, 836-842.
- Timmermann, S. (2012). To "Age in Place" or not...that is the question. *Journal of Financial Service Professionals*, 66(1), 24-26.
- Tseng, S.Z., & Want, R.H. (2001). Quality of life and related factors among elderly nursing home residents in southern Taiwan. *Public Health Nursing*, *18*, 304-311.
- Uchino, B.N. (2009). Understanding the links between social support and physical health: A lifespan perspective with emphasis on the separability of perceived and received support. *Perspectives on Psychological Science*, 4(3), 236-255.

- Umberson, D., & Montez, J.K. (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior*, *51*(Suppl), S54-S66. DOI:10.1177/0022146510383501.
- Valtorta, N.K., Kanaan, M., Gilbody, S., Ronzi, S., & Hanratty, B. (2016). Loneliness and social isolation as risk factors for coronary heart disease and stroke: Systematic review and meta-analysis of longitudinal observational studies. *Heart, 102*, 1009-1016. DOI:10.1136/heartjnl-2015-309242
- Van Beljouw, I.M.J., Van Exel, E., de Jong Gierveld, J., Comijs, H.C., Heerings, M., Stek, M.L., & Van Marwijk, H.W.J. (2014). "Being all alone makes me sad": Loneliness in older adults with depressive symptoms. *International Psychogeriatrics*, 26(9), 1541-1551. DOI:10.1017/X1041610214000581.
- Van Tilburg, T., Dykstra, P., Liefbroer, A.C., & Van Groenou, M.B. (2003). Sourcebook of *living arrangements and social networks of older adults in the Netherlands*. The Hague: Netherlands Interdisciplinary Demographic Institute.
- VanderWeele, T.J., Hawkley, L.C., Thisted, R.A., & Cacioppo, J.T. (2011). A marginal structural model analysis for loneliness: Implications for intervention trials and clinical practice. *Journal of Consulting and Clinical Psychology*, 79(2), 225-235. DOI:10.1037/a0022610.
- Vaux, A. (1988). Social support: Theory, research, and intervention. New York, NY: Praeger.
- Venes, D. (2013). *Taber's cyclopedic medical dictionary*. Philadelphia, PA: F.A. Davis Company.
- Victor, C.R. (2015). Loneliness and later life: Concepts, prevalence, and consequences. In A. Sha'ked, & A. Rokach (Eds.), Addressing loneliness: Coping, prevention and clinical interventions (180-200, Chapter 12). New York, NY: Routledge/Taylor & Francis Group.
- Victor, C., Grenade, L., & Boldy, D. (2006). Measuring loneliness in later life: A comparison of differing measures. *Reviews in Clinical Gerontology*, 15, 63-70. DOI:10.1017/S0959259805001723.
- Victor, C.R., Scambler, S., Bond, J., & Bowling, A. (2000). Being alone in later life: Loneliness, social isolation and living alone. *Reviews in Clinical Gerontology*, *10*(04), 407-417.
- Victor, C.R., Scambler, S., & Bowling, A. (2008). Social world of older people: Understanding loneliness and social isolation in later life. Berkshire, GB: Open University Press.

von Witzleben, H.D. (1958). On loneliness. Psychiatry, 21(1), 37-43.

Walsh, E.G., Wiener, J.M., Haber, S., Bragg, A., Freiman, M., & Ouslander, J.G. (2012).

Potentially avoidable hospitalizations of dually eligible Medicare and Medicaid beneficiaries from nursing facility and home- and community-based services waiver programs. *Journal of the American Geriatrics Society*, *60*, 821-826. DOI:10.111/j.1532-5415.2012.03920.x.

- Warner, D.F., & Adams, S.A. (2016). Physical disability and increased loneliness among married older adults: The role of changing social relations. *Society and Mental Health*, 6(2), 106-128. DOI:10.1177/2156869315616257.
- Warner Schae, K., Wahl, H., Mollenkopf, H., & Oswold, F., Eds. (2003). *Aging independently: Living arrangements and mobility*. New York, NY: Springer Publishing Company.
- Weeks, D.G., Michela, J.L., Peplau, L.A., & Bragg, M.E. (1980). Relation between loneliness and depression: A structural equation analysis. *Journal of Personality and Social Psychology*, 39(6), 1238-1244.
- Weiss, R.S. (1973). *Loneliness: The experience of emotional and social isolation*. Cambridge, MA: The MIT Press.
- Wenger, G.C., & Burholt, V. (2004). Changes in levels of social isolation and loneliness among older people in a rural area: A twenty-year longitudinal study. *Canadian Journal on Aging*, 23(2), 115-127.
- Wood, M.M. (1953). *Paths of loneliness: The individual isolated in modern society*. New York, NY: Columbia University Press.
- World Health Organization. (2015). *World report on ageing and health*. Geneva, Switzerland: World Health Organization.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15, 215-228. DOI:10.1080/08870440008400302.
- Yardley, L. (2017). Demonstrating the validity of qualitative research. *The Journal of Positive Psychology*, *12*(3), 295-296. DOI:10.1080/17439760.2016.1262624.
- Zilboorg, G. (1938). Loneliness. The Atlantic (1932-1971), 161(000001), 45-54.
- Zimet, G.D., Powell, S.S., Farley, G.K., Werkman, S., Berkoff, K.A., (1990). Psychometric characteristics of the multidimensional scale of perceived social support. *Journal of Personality Assessment*, 55, 610-617. DOI:10.1080/00223891.1990.9674095.