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Post-Fall Decision Making Among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

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POST-FALL DECISION MAKING AMONG OLDER WOMEN LIVING IN CONTINUING
CARE RETIREMENT COMMUNITIES: A MIXED METHODS STUDY

by

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DEDICATION

To my parents, who never once doubted that I could reach this goal, merci pour tout!

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This dissertation would not have been possible without the help of the following individuals and organizations. First and foremost, I would like to thank my Dissertation Chair, Dr. Daniela B. Friedman, for being an exceptional mentor and role model. Thank you for guiding me through this doctorate! To Dr. DeAnne K. Hilfinger Messias, thank you for all the hours you spent teaching me rigorous qualitative research. To Dr. Mindi Spencer, thank you for your help and for believing in this project – thanks Nana! To Dr. Susan C. Miller, thank you for your feedback along the way. To Dr. Robert McKeever and Mrs. Wilma Sims, thank you for your help with my quantitative analyses. Thank you to my study participants for contributing to our understanding of falls. Thank you to all the community partners, including the Office for the Study of Aging, Leading Age South Carolina, the SC Lieutenant Governor's Office on Aging, AARP South Carolina, and all of the participating CCRCs, senior centers, and County Councils on Aging. A special thanks goes out to: Denise Heimlich, Tacey Gohean, Dan Smith, Tricia Richardson, Marian F. Youorski, Vera Walling, Nancy Reyes, Katie Jayne, Joy Hill, Mary Gilliam, Tiffany Keyes, Abbie Slater, Carolyn Gambrell, Vickie Moody, Mary Kessler, Mike Brown, Lee Hill, Peter Balsamo, Pam Dukes, Dave Smith, and Victor Hirth. Thank you to the Canadian Institutes of Health Research for funding my doctoral dissertation and to the Office of the Provost for the dissertation funds. Last but not least, I am grateful to my family, my husband, and my friends for their support throughout this doctoral journey.

ABSTRACT

Introduction: One in every three adults over the age of 65 experiences a fall every year, with women experiencing more falls than men. Falls can affect how older women perceive themselves and their independence. The purpose of this study was to examine older women's health decision making after experiencing a fall. **Methods:** I conducted semi-structured interviews with 17 older women living independently in continuing care retirement communities (CCRCs) who had experienced a fall within the previous six months and 11 individuals the women identified as being involved in their post-fall decision making. I also conducted an exploratory survey on post-fall decision making with 130 older women (65 from CCRCs; 65 from non-institutional homes) who had experienced a fall within the previous 12 months. I analyzed the qualitative data using open and axial coding. I analyzed the quantitative data using bivariate associations and ordinary least square regression. **Results:** Women used different approaches and decisions to respond to a fall and engaged in substantive work to get "back to normal". This work entailed balancing issues of privacy and independence with their need for personal assistance or aids. Women accessed, accepted, or rejected information from family members and professionals after their fall based on their openness to others' advice, their assessment of the credibility of the potential information sources, and the relationship patterns they established with these sources. Older women also made medical, corrective, and social decisions after their falls. Making medical decisions

resulted in greater decisional conflict compared to other types of decisions. Women's familiarity with assisted living and level of health literacy also predicted how much decisional conflict they would experience in their decision-making process. **Discussion:** This study examined decisions older women made after a fall, how they made these decisions, and what factors influenced these decisions. Increased awareness, understanding, and communication of these post-fall approaches and decisions is needed to help older women, family members, and professionals work together to enhance older women's post-fall decision making, lower their decisional conflict, and assist them in regaining their health and quality of life.

Key Words: Older Women; Information Sources; Falls; Decision Making; Decisional Conflict; Health Literacy; Continuing Care Retirement Communities; Qualitative Interviews; Exploratory Survey

PREFACE

This dissertation is the culmination of my five years of doctoral studies. This dissertation is original, unpublished, and independent work.

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LIST OF ABBREVIATIONS

CCRC.....	Continuing Care Retirement Community
CDC	Centers for Disease Control and Prevention
RQ.....	Research Question
SC.....	South Carolina
U.S.	United States

CHAPTER 1

INTRODUCTION

Falls are an important public health issue in older age. The definition of a fall is “inadvertently coming to rest on the ground, floor, or other lower level, excluding intentional change in position to rest in furniture, wall, or other objects” (World Health Organization, 2007). Each year, more than one in three Americans over the age of 65 will experience a fall (Centers for Disease Control and Prevention, 2015a; Lord, Sherrington, Menz, & Close, 2007). Women aged 65 and older are more likely than men to fall (Schiller, Kramarow, Dey, & National Center for Health Statistics, 2007; Stahl & Albert, 2015; World Health Organization, 2007) with this likelihood and severity of falls increasing with age (Nachreiner, Findorff, Wyman, & McCarthy, 2007; Stevens & Sogolow, 2005; Werner, 2011). Non-fatal injuries may include spinal cord and brain injury, fractures, sprains, strains, and dislocations of the hip, thigh, knee, lower leg, ankle, foot, back, wrist and hand, among others (Stevens, Corso, Finkelstein, & Miller, 2006; World Health Organization, 2007; Wu, Keeler, Rubenstein, Maglione, & Shekelle, 2010). Falls cost the United States (U.S.) health care system approximately 34 billion dollars per year in direct medical costs (Stevens, et al., 2006). These costs include inpatient hospitalizations, hospital outpatient visits, emergency room visits, medical office visits, home health care, and prescription drugs (Roudsari, Ebel, Corso, Molinari, & Koepsell, 2005; Stevens, et al., 2006). The cost of fall injuries is expected to increase to 67.7 billion dollars per year by 2020 (Centers for Disease Control and Prevention, 2015c).

Falling is a major concern in the lives of older women (Smith, Ory, & Larsen, 2010; Stahl & Albert, 2015). It is considered a trigger event that can cause older women to modify their self-perceptions, which can consequentially change how they maintain their health and independence (Boyd & Stevens, 2009; Dollard, Barton, Newbury, & Turnbull, 2012; Gopaul & Connelly, 2012). Some researchers have examined older adults' emotional and psychological responses to falling (e.g., fear of falling) and subsequent avoidance of activities (Ballinger & Payne, 2002; Calhoun et al., 2011; Jørstad, Hauer, Becker, & Lamb, 2005; Yardley & Smith, 2002), **however very few have explored specifically the post-fall decision-making process and how it is experienced by independent women living in continuing care retirement communities (CCRCs).**

CCRCs are a type of residential campus where independent older adults have the opportunity to age in place in their cottages or apartments, but can move to assisted living and skilled nursing if they require more care (Kohl, 2010; U.S. Census Bureau, 2012; Zarem, 2010). Older adults residing in a CCRC have access to a variety of services including meals, housekeeping, social and leisure services, as well as personal care (U.S. Census Bureau, 2012; Zarem, 2010).

Experiencing a fall in a CCRC may require specific accommodations such as wearing and using a life alert system device to alert onsite first responders and staff, using a walker, being accompanied by an adult sitter, or being transferred to a higher level of care (Krout, Moen, Holmes, Oggins, & Bowen, 2002; Young, 2009). Little is known about how older women in CCRCs make these post-fall decisions and what factors influence these decisions.

Scholars of various disciplines have examined decision making among older adults, including those from psychology (Finucane & Gullion, 2010; Mata, 2007), public health (Finucane et al., 2002; Freeman, Gange, Muñoz, & West, 2006), nursing (Murray, Miller, Fiset, O'Connor, & Jacobsen, 2004; Murray, O'Connor, Fiset, & Viola, 2003), and medicine (Belcher, Fried, Agostini, & Tinetti, 2006; Wong et al., 2012). However, among all these disciplines, there are very few published studies of decision making among older adults in the aftermath of trigger events such as falls, and less on how these events may shape their health and perspectives in older adulthood (Guttman, 1978; Shawler, Rowles, & High, 2001). **The overall goal of this study was to explore post-fall decision making of independent older women living in CCRCs.** This study was guided by the Disablement Process Model (Verbrugge & Jette, 1994) and included three specific aims to better understand older women's post-fall decision-making processes.

Specific Aims

Aim 1.

The goal of Specific Aim 1 was to explore the interpretations and personal meanings associated with falls and post-fall decisions of older women living in CCRCs.

RQ1. What meanings do older women residing in CCRCs associate with their experience of a fall?

RQ2. What decisions do older women residing in CCRCs make after a fall and what are the outcomes of those decisions?

Aim 1 Methods. I conducted individual, in-depth, semi-structured interviews with a purposive sample of 17 older women living in one of two CCRCs and experienced a fall within the previous six months. Each interview lasted between 30 minutes and 2.5

hours. Participants also completed a 10-item demographic survey. I analyzed the qualitative data using inductive open and axial coding (Strauss & Corbin, 1998; Thomas & Harden, 2008) to find relevant themes throughout the interviews. I analyzed the quantitative data using IBM SPSS[®] Statistics 22.0 (IBM Corp., 2013) to run nonparametric frequencies and percentages. I submitted a manuscript describing these findings to the journal *Health Care for Women International* (See Chapter 4, Manuscript 1).

Aim 2.

The goal of Specific Aim 2 was to examine how specific interpersonal factors and information sources relate to post-fall decision making among older women living in CCRCs.

RQ3. Who or what do older women residing in CCRCs identify as their main sources of information when making post-fall decisions?

RQ4. What type of information and advice do these sources provide?

RQ5. How do older women residing in CCRCs assess the quality, credibility, and trustworthiness of these sources when making post-fall decisions?

RQ6. If a person is identified as the older woman's main source of information, how does this person view his/her role in the older woman's post-fall decision making?

Aim 2 Methods. I conducted individual, in-depth, semi-structured interviews with a purposive sample of 17 older women who experienced a fall within the previous six months (primary informants). I also conducted semi-structured interviews with 11 individuals the women identified as being involved in their post-fall decision-making processes such as their husbands, adult children, and health care professionals (secondary

informants). The interviews with the primary informants lasted between 30 minutes and 2.5 hours and the interviews with the secondary informants lasted between 20 minutes and 1.5 hours. All participants also completed a brief demographic survey. I analyzed the qualitative data using inductive open and axial coding (Strauss & Corbin, 1998; Thomas & Harden, 2008) and computed nonparametric frequencies and percentages using IBM SPSS® Statistics 22.0 (IBM Corp., 2013). I submitted a manuscript describing the findings of Aim 2 to *Ageing and Society* (See Chapter 4, Manuscript 2).

Aim 3

The goal of Specific Aim 3 was to examine how specific intrapersonal factors relate to post-fall decision making among older women living in CCRCs and in non-institutional homes.

RQ7. How are older women's self-rated health, history of falls, severity of falls, and health literacy associated with their post-fall decision making?

RQ8. How are older women's familiarity with care options and openness to care options associated with their post-fall decision making?

RQ9. How are older women's post-fall decisions associated with decisional conflict?

Aim 3 Methods. I administered an in-person paper-pencil exploratory survey to 65 independent older women living in CCRCs and another 65 independent older women living in non-institutional homes across the state of South Carolina. All women had experienced a fall within the previous 12 months and had suffered at least a minor injury. The purpose of the survey was to investigate older women's post-fall decisions, to examine whether there were any associations between different intrapersonal factors and post-fall decision making, and to examine the role of decisional conflict in the decision-

making process. I used IBM SPSS Statistics 22.0 (IBM Corp., 2013) to analyze the data using nonparametric frequencies and percentages, one-way analyses of variance, and ordinary least square multiple regression. I will be submitting a manuscript describing the findings from Aim 3 to the journal *Quality of Life Research* (See Chapter 4, Manuscript 3).

Significance

This unique research contributes to the field of public health by being one of the first studies to explore post-fall decision making among older women living in CCRCs and providing a greater understanding of precisely how older women manage these fall situations in terms of their health and independence. The study findings can help older women explore different approaches and decisions after a fall and determine the best way to recover their health and quality of life. It can also help family members and professionals (e.g., health care professionals) understand this decision-making process, get involved, and provide support and advice to these women as they try to navigate their post-fall circumstances. CCRC administrators and staff across the country can also use these results to provide better quality care and services to their clients as they experience a fall in this setting. Finally, these important study findings on post-fall decision making can also be included in future falls prevention programs and initiatives.

Preview

This dissertation is organized as follows: In Chapter 2, Background and Significance, I synthesize the literature on falls and decision making to justify the importance of conducting this study. In Chapter 3, Methods, I detail the methodology I used for this research. In Chapter 4, Results, I present the study findings in the format of

three academic manuscripts submitted or ready to be submitted to *Health Care for Women International*, *Ageing and Society*, and *Quality of Life Research*. Finally, in Chapter 5, Conclusions and Implications, I summarize the results of this study and discuss its research and practical implications.

CHAPTER 2

BACKGROUND AND SIGNIFICANCE

In this chapter, I review the literature on falls, falls prevention, post-fall experiences, CCRCs, decision making, shared decision making, decision making in older adulthood, and decision making after an older woman experiences a fall to show the gaps in the literature and the importance of studying post-fall decision making among older women living in CCRCs. I finish this chapter by briefly presenting the significance of this study, followed by a description of my preparation to conduct this research.

Falls

A fall can be defined in different ways. For my particular research, a fall refers to unintentionally “coming to rest on the ground, floor, or other lower level” (Lamb, Jørstad-Stein, Hauer, & Becker, 2005, p.1619). Falls can happen during any activity, such as walking, carrying objects, or reaching for something, anytime during the day or at night, and anywhere, including the bedroom, bathroom, living room, kitchen, stairs, and public places (Lord, et al., 2007; Nachreiner, et al., 2007). Falls are an important public health issue, resulting in significant morbidity and mortality among older adults (Ambrose, Paul, & Hausdorff, 2013; Kalyani et al., 2010; Rubenstein, 2006). Each year, more than one in three Americans over the age of 65 experiences a fall (Centers for Disease Control and Prevention, 2006, 2015a, 2015d, 2015e; Hausdorff, Rios, & Edelberg, 2001; South Carolina Department of Health and Environmental Control, 2010). Unintentional falls are the leading cause of non-fatal injuries in adults 65 years of age and

older (Centers for Disease Control and Prevention, 2015d). Older women are more likely than older men to fall (Rossat et al., 2010; Schiller, et al., 2007; Stevens & Sogolow, 2005; World Health Organization, 2007). This risk of falling increases with age due to declines in physiological health such as changes to the cardiovascular, visual, and musculoskeletal systems (Ambrose, et al., 2013). However, fall risks remain greater for women of all age groups compared to men (Curtin, 2005; Levi, Segal, & Martin, 2015; Morley et al., 2013). In South Carolina, women are two times more likely to experience a non-fatal fall injury compared to men (Ambrose, et al., 2013; Curtin, 2005; South Carolina Department of Health and Environmental Control, 2010). These non-fatal injuries may include spinal cord and brain injury, fractures, sprains, strains, and dislocations of the hip, knee, and wrist, among others (Stevens, et al., 2006; World Health Organization, 2007).

Falls in older adulthood cost the U.S. health care system approximately \$30 billion dollars in direct medical costs (Centers for Disease Control and Prevention, 2015d; Stevens, et al., 2006). These costs include inpatient hospitalizations, hospital outpatient visits, emergency room visits, medical office visits, home health care, and prescription drugs (Roudsari, et al., 2005; Stevens, et al., 2006). Medical costs for older women who experience a fall are double to triple the costs of older men (Stevens, et al., 2006), suffering primarily from costly fractures (Centers for Disease Control and Prevention, 2015b). As the population ages, the number of injurious falls is expected to increase (Levi, et al., 2015), with the cost of fall injuries to reach 67.7 billion dollars per year by 2020 (Centers for Disease Control and Prevention, 2015c).

Most falls in older adulthood are multifactorial and not due to simple random events (Delbaere et al., 2010; Lord, et al., 2007; Tinetti & Kumar, 2010). Falls may be explained by the disablement process which occurs in older age, where a variety of risk factors lead to an acute condition or event (e.g., a fall) and to short- or long-term disability (Jette, 2006, 2009; Verbrugge & Jette, 1994). These risk factors that start the disablement process can be classified into four dimensions: biological, behavioral, environmental, and socioeconomic factors (World Health Organization, 2007). Biological factors refer to human characteristics such as age, gender, race, as well as chronic illnesses such as Parkinson's disease and osteoporosis. Behavioral risk factors refer to human actions, emotions, or choices, such as alcohol use and a sedentary lifestyle. Environmental risk factors include the physical environment such as slippery surfaces, uneven sidewalks, and poor lighting. Socioeconomic risk factors refer to social and economic conditions, such as low income, low education, and limited access to health care. All of these factors may interact and contribute to falls in older adults (Delbaere, et al., 2010; Kalyani, et al., 2010; Tinetti & Kumar, 2010; World Health Organization, 2007); the greater the number of factors, the greater the risk of falls (Ambrose, et al., 2013).

Experiencing a fall can have physical, psychological, and social consequences, even for older adults who do not suffer a fall injury (Bloch et al., 2014; Finlayson & Peterson, 2010; Kenny, Romero-Ortuno, & Cogan, 2013). The term *post-fall syndrome* was assigned to help explain some of these fall consequences, especially as it relates to a loss of confidence and a fear of falling (Bailey, Jones, & Goodall, 2014; Boyd & Stevens, 2009; Landers, Durand, Powell, Dibble, & Young, 2011; Patil, Uusi-Rasi, Kannus,

Karinkanta, & Sievänen, 2014). Falls can result in restriction or avoidance of activity, damage to one's identity, and a reduction in one's quality of life (Boyd & Stevens, 2009; Lord, et al., 2007). It is not surprising that between 75 to 80 percent of all non-injurious falls are never reported to health professionals (World Health Organization, 2004) and that even injurious falls are underreported (Ambrose, et al., 2013; Beaudette, 2011). Fortunately, several interventions can help older adults who have fallen prevent more falls in the future (Centers for Disease Control and Prevention, 2015a, 2015e; World Health Organization, 2004).

Falls Prevention

Research on falls in the last few decades has focused on falls prevention, and more specifically on screening older adults for fall risks, removing environmental hazards that cause falls, and developing effective falls prevention programs (Bergland & Wyller, 2004; de Vries et al., 2010; Ferrer et al., 2014; Gillespie et al., 2012; Kenny et al., 2011; Lee et al., 2013; Olsson, Kristensson, Midlöv, Ekdahl, & Jakobsson, 2014; Palvanen et al., 2014; Rubenstein, 2006; Wu, et al., 2010). Some common exercise and multifaceted falls prevention and education programs that have shown to increase strength, balance, and reduce fear of falling among older adults include: "A Matter of Balance" (Maine Health, n.d.; Tennstedt et al., 1998; Ullmann, Williams, & Plass, 2012), "Stepping On" (Clemson et al., 2004; Clemson & Swann, 2008), and "Tai Chi: Moving for Better Balance" (Li, 2014; Li, Harmer, Fisher, & McAuley, 2004; Li et al., 2008), which was recently renamed "Tai Ji Quan: Moving for Better Balance" (National Council on Aging, 2015). There also exist national initiatives and toolkits such as the National Council on Aging's Falls Free Initiative (National Council on Aging, 2005) and the Centers for

Disease Control and Prevention (CDC)'s National Center for Injury Prevention and Control "Stopping Elderly Accidents, Deaths & Injuries (STEADI) Tool Kit" (Centers for Disease Control and Prevention, 2015e) that help to raise awareness of falls and fall-related injuries as well as use multifactorial approaches to reduce the incidence of falls among older adults (Tinetti & Kumar, 2010).

Falls prevention programs continue to be crucial in preventing and/or delaying the disablement process among older adults. However, despite having these prevention programs, falls and fall-related injuries among older adults continue to occur every day (Child et al., 2012). There has also been a limited focus on what happens after a fall and how older adults manage their fall events (Roe et al., 2008; Rubenstein et al., 2004; Tinetti & Kumar, 2010). Due to the prevalence and frequency of falls among older adults, more emphasis should be placed on their post-fall experiences.

Post-Fall Experiences

Post-fall assessments are necessary to better understand internal and external causes of falls (Gray-Miceli, Ratcliffe, & Johnson, 2010; Nyman, 2011; Tirrell et al., 2015; Zecevic, Salmoni, Lewko, Vandervoort, & Speechley, 2009). Some of these internal causes include physical weakness and poor balance, vision loss, and medication interactions; some external causes of falls are poor lighting, rugs, and slippery surfaces caused by water or ice (Centers for Disease Control and Prevention, 2008; Gray-Miceli, et al., 2010). These post-fall assessments can also provide insight into how older adults explain and interpret their falls (Carroll, Dykes, & Hurley, 2010; Høst, Hendriksen, & Borup, 2011; Roe, et al., 2008) and how older women's interpretations differ from health care providers' views of the fall (Zecevic, Salmoni, Speechley, & Vandervoort, 2006).

A number of studies have examined the post-fall experiences of older adults. Roe and colleagues (2008) interviewed 27 older adults who had fallen and found that those who reflected on their fall developed strategies to prevent future falls. Those who did not seek to understand how and why they fell remained fearful of falling (Roe et al., 2008). Høst and colleagues (2011) came to similar conclusions with their interviews of 14 Scandinavian older adults. In their study, those who fell managed the consequences of their fall by restricting their activities rather than addressing their fall risk factors (Høst, et al., 2011). Ullmann, Williams, and Plass's study (2012) with 162 apartment dwelling older adults found that participants who reported poorer self-rated health and dexterity issues were more likely to blame their fall on their own limitations; in contrast, those who reported better self-rated health and were falling outdoors were more likely to attribute the cause of the fall to their surroundings (Ullmann, et al., 2012). Dollard and colleagues' study (2012) with nine community-dwelling older people in Australia found that older adults had a negative view of falling and tried to dissociate themselves from those who *usually* fall to better manage this threat to their identity (Dollard, et al., 2012). Similarly, Stewart and McVittie's study (2011) with eight Scottish house-bound older adults after their falls revealed that older adults' post-fall experiences included managing some loss of independence, confidence, and social identity. These examples provide an indication of the types of qualitative and quantitative studies that have explored falls and the consequences of those falls. These post-fall assessments can help health professionals refer an older adult to the best fall prevention intervention following her or his fall and/or fall-related injury (Dickinson et al., 2011). They can also help family, caregivers, and

staff provide care to an older adult after a fall, and not exacerbate an older adult's loss of independence (De la Cuesta Benjumea & Roe, 2015; Stewart & McVittie, 2011).

It is important to note that a fall is a gendered concept and interpreted differently by men and women (Horton, 2007; Painter & Elliott, 2009). For example, older women may have a tendency to blame themselves or others more frequently for their falls, while older men feel more responsible for reducing their own fall risks. Moreover, this attribution process can also influence how an older woman perceives herself after a fall, as well as the decisions she makes regarding her health and independence (Boyd & Stevens, 2009; Dollard, et al., 2012; Gopaul & Connelly, 2012; McInnes, Seers, & Tutton, 2011; Nachreiner, et al., 2007; Patil, et al., 2014). I present more literature on older women and their decision making after a fall on page 23. Nonetheless, the environment and location where the older woman lives may also influence the type of decisions she makes to maintain her health and regain her quality of life after a fall (Aird & Buys, 2015; Croucher, Hicks, & Jackson, 2006; Lien, 2013; Wells & Laquatra, 2009).

Continuing Care Retirement Communities

Continuing care retirement communities (CCRCs) are environments where older women may experience a fall. A CCRC is a residential campus that offers different types of housing and levels of care in the same location under one contract, including independent living in apartments or cottages, assisted living, skilled nursing, and memory care or dementia unit (Centers for Medicare & Medicaid Services, 2015; SC Consumer Affairs, 2007). Residents generally move to a CCRC in independent living, but gradually move to another level of care as their health and needs change over time (Centers for Medicare & Medicaid Services, 2015; Hunt, Feldt, Marans, Vakalo, & Pastalan, 2015;

Morrison, Frisch, Bennett, & Gurland, 2013). Benefits of moving to a CCRC include lifetime access to housing and health care, freedom from home maintenance, opportunity to remain independent, as well as supportive services, such as personal care, daily meals, housekeeping, security, transportation, and social and leisure services (AARP, 2015; Hunt, et al., 2015; SC Consumer Affairs, 2007; Zarem, 2010). Moving to a CCRC requires a substantial entry fee, which can range from \$100,000 to \$1 million depending on the location, as well as fixed monthly payments (AARP, 2015; Centers for Medicare & Medicaid Services, 2015; Zarem, 2010).

There are approximately 1,900 licensed CCRCs in the United States, of which 38 are located in South Carolina (SC Consumer Affairs, 2015; Zarem, 2010). The average age of entry of new CCRC residents is between 80 to 83 years old, and approximately 70 to 85 percent of all residents are women (Zebolsky, 2014). The majority of residents (95%) have a high school education or higher (Zarem, 2010).

CCRCs are becoming more and more popular as a site for health promotion research. For example, researchers have examined relocating to a CCRC (Ayalon, 2015; Ayalon & Greed, 2015; Groger & Kinney, 2007; Krout, et al., 2002) as well as transitioning to another level of care (Kelsey, Laditka, & Laditka, 2010; Shippee, 2009), preferences of a CCRC for the place of death (Hays, Galanos, Palmer, McQuoid, & Flint, 2001; Matzo & Hijjazi, 2008), social support in CCRCs (Ayalon & Green, 2013; Shippee, 2012; Waldron, Gitelson, & Kelley, 2005), alcohol use in CCRCs (Resnick, 2003; Sacco et al., 2015), physical activity in CCRCs (Resnick & D'Adamo, 2011; Wrights et al., 2015) and fall prevention initiatives (Harris, 2014; Kerr et al., 2012; Lord

et al., 2003; Rosenberg et al., 2009), including willingness to adopt smart home technologies to prevent falls (Courtney, Demiris, Rantz, & Skubic, 2008).

Few researchers, however, have focused on falls among older adults living in CCRCs (Resnick, 1999; Resnick & Junlapeeya, 2004) and post-fall decisions in this setting remain understudied. Independent older women living in CCRCs have access to many resources (e.g., staff and social networks) and supportive services (e.g., personal care, housekeeping, etc.), which can help them age in place (Shippee, 2009). An older woman may therefore consider these various social conditions when making decisions about her health and independence after a fall. A CCRC, where independent women make up more than half of the population and experience more falls than men (Zebolsky, 2014), is an important setting to examine how older women make post-fall health decisions (Høst, et al., 2011; Lamarche, Gammage, Klentrou, & Adkin, 2014; Yardley & Smith, 2002).

Decision Making

Decisions are choices or actions to choose from and are based on one's beliefs in achieving a goal (Tversky & Kahneman, 1981). A decision is the "selection of an action with the aim of producing satisfying outcomes" (Yates & Patalano, 1999, p.32). Decision making is a problem solving process that involves recognizing a need, identifying and evaluating different alternatives in terms of gains or losses, and choosing between alternative courses of action to bring desirable outcomes (Moen & Erickson, 2001; O'Connor, Jacobsen, & Stacey, 2002; Yates & Patalano, 1999). This decision-making process is important for the person making the decision to value the chosen alternative (O'Connor, et al., 2002).

Decision making may be challenging because some alternatives may have both desirable and undesirable outcomes, and more than one option can bring the desired results (Higgins, 2000, 2005). Decisional conflict (Janis & Mann, 1977; O'Connor, 1995; O'Connor, et al., 2002) refers to this uncertainty in the decision-making process, where one has difficulty choosing a course of action (O'Connor, 1995; O'Connor, et al., 2002). Decisional conflict can be manifested by verbalizing one's uncertainty about the choices, verbalizing the undesired consequences of some actions, alternating and hesitating between choices, delaying decision making, as well as through physical signs of distress (O'Connor, 1993). Two reasons may contribute to decisional conflict in the decision-making process: 1) people may be uncertain because the different alternatives they face all have potential advantages and disadvantages; and 2) some modifiable factors may make the decision making difficult. Some of these factors include lack of knowledge about options and outcomes, lack of skills and/or self-confidence, lack of support, lack of resources, unclear values or uncertainty about personal importance, unrealistic expectations, unclear perceptions of others including opinions, and social pressure (O'Connor, et al., 2002). Some of these modifiable factors, including knowledge about options and perceptions of others, are intrapersonal and interpersonal factors that influence the decision-making process.

Women usually report greater decisional conflict compared to men (O'Connor, et al., 2002). This may be explained in part by women's caregiving role (e.g., wives, mothers, daughters, nurses, etc.), which increases their responsibility in making the right decision (Bunn et al., 2006; Chang, Schneider, & Sessanna, 2011; Stacey, Pomey, O'Connor, & Graham, 2006; Tercyak et al., 2007). It can also be explained by women's

greater need for involvement in health decision making (Levinson, Kao, Kuby, & Thisted, 2005; Say, Murtagh, & Thomson, 2006). Wanting to be part of the decision making may also involve lack of knowledge and understanding of all the different options available, resulting in greater decisional conflict and uncertainty. Decisional conflict particularly among older women has been studied in the past, including for breast cancer treatment (D'Alimonte et al., 2012; Stacey, O'Connor, DeGrasse, & Verma, 2001), osteoporosis (Cranney et al., 2002), and hormone replacement therapy (Légaré et al., 2003), among others.

Although decisional conflict has not yet been studied in the context of falls, women may also experience decisional conflict when making post-fall decisions. Some post-fall decisions, such as using a walker, may place women in a state of uncertainty as they juggle and balance conflicting priorities (e.g., independence versus safety; Luz, Bush, & Shen, 2015). Decisional conflict may lead to greater psychological discomfort (van Harreveld, Rutjens, Rotteveel, Nordgren, & van der Pligt, 2009), which in older women's cases may exacerbate their already negative feelings about falling.

Several tools such as decision aids can help lower decisional conflict and engage individuals in the decision-making process (Lewis et al., 2010; Montori et al., 2011; Schonberg et al., 2014; Stacey et al., 2012; Stacey et al., 2014; Wong, et al., 2012). Different frameworks, such as the Ottawa Decision Support Framework, can also facilitate individuals and groups' decision making (O'Connor et al., 1998; Ottawa Hospital Research Institute, 2015). Developed by O'Connor and colleagues (1998), the Ottawa Decision Support Framework may be used to assist long-term health decisions that are motivated by new diagnoses (e.g., cancer), transitions (e.g., pregnancy), or

circumstances (e.g., a fall). The framework can help all the participants involved in the decision – e.g., the patient, the family, and the health care provider – identify and address some of the modifiable factors for better decision making (Cranney, et al., 2002; Ottawa Hospital Research Institute, 2015). This study does not focus on these types of frameworks or tools, but does include how different sources of information may be involved in the shared decision-making process.

Shared Decision Making. Shared decision making refers to the mechanism by which, in a medical encounter, a doctor and a patient share information, consider the patient's individual preferences, and increase the patient's sense of autonomy and control over the decisions affecting his or her health (Charles, Gafni, & Whelan, 1997; Charles, Gafni, & Whelan, 1999; Charles, Whelan, Gafni, Willan, & Farrell, 2003; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Légaré et al., 2010; Légaré et al., 2012; Makoul & Clayman, 2006; Sandman & Munthe, 2010; Scholl et al., 2011). The process is shared because it involves two-way communication between the health care professional and the patient where the health care professional usually offers options and describes the risks and benefits of each option, while the patient expresses her or his preferences and values (Charles, et al., 1999). The interaction may be led by the doctor or the patient, but the other acknowledges, agrees, and/or shares his/her views and opinions on the options and alternatives available (Makoul & Clayman, 2006).

Several models explain how to reach shared decision making in medical practice (Charles, et al., 1999; Elwyn et al., 2012; Makoul & Clayman, 2006). One such model by Elwyn and colleagues (2012) uses the following three steps to accomplish shared decision making: (1) introducing the choice; (2) describing options and using decision

aids to increase knowledge and understanding of the options; and (3) helping patients explore their preferences and make a final decision (Elwyn, et al., 2012).

Despite these models, several barriers including time constraints and patient characteristics continue to impede shared decision making in the medical setting (Légaré, Ratté, Gravel, & Graham, 2008). Studies still suggest that patients prefer to delegate the decision making authority to their health care provider (Arora & McHorney, 2000; Levinson, et al., 2005; Makoul & Clayman, 2006). Women, however, are found to be more active than men in this decision-making process (Arora & McHorney, 2000; Levinson, et al., 2005; Say, et al., 2006).

Shared decision making is not limited to patient-provider communication. On the contrary, it may involve a variety of individuals, such as the patient's spouse, an adult child, other relatives, or friends (Barry & Edgman-Levitan, 2012; Friedman, Thomas, Owens, & Hébert, 2012; Gilbar & Gilbar, 2009; Hesse et al., 2005; Jones, Steeves, & Williams, 2010; Kon, 2010; Popejoy, 2005; Winzelberg, Hanson, & Tulskey, 2005). This informal care support may help facilitate patient or doctor understanding, as well as help the patient get involved in her or his own care (Clayman, Roter, Wissow, & Bandeen-Roche, 2005; Eggly et al., 2006; Jones, et al., 2010; Wolff & Roter, 2011).

Shawler, Rowles, and High (2001) group these interpersonal sources into what they call a *decision-making constellation*. All individuals involved in the decision-making process are part of the decision-making constellation. For example, in the case of an independent older woman experiencing a fall in a CCRC, her decision-making constellation may include her spouse, adult children, friends, physician, nurse, a certified nursing assistant, social worker, and other residents, i.e., any individual that is involved

in her decision-making process (Bertsch, 2005; Popejoy, 2005; Shawler, et al., 2001; Waldron, Gitelson, & Kelley, 2005). Members of the constellation can provide emotional support, assistance, and advice in the decision making (Shawler, et al., 2001; Waldron, Gitelson, Kelley, & Regalado, 2005). They may be particularly useful in providing an older woman with important health information that she may not seek herself (Hesse, et al., 2005; Hummert, 2007; Ryan, Anas, & Friedman, 2006). Effective communication between an older woman and her constellation is key during the post-fall decision-making process to ensure she knows about the different services and options that are available to her and that she is empowered to access the care that she needs (Shawler, 2006).

Several communication issues may arise, however, during an interpersonal communication with an older adult. Many individuals may unconsciously stereotype older adults due to their age, their dependency status, and their new disabilities (Chasteen & Cary, 2015; Hummert, Garstka, Ryan, & Bonnesen, 2004; Nussbaum, Pitts, Huber, Krieger, & Ohs, 2005; Ryan, Hummert, & Boich, 1995). Others may use elderspeak and patronizing communication, such as simplified vocabulary and repetition, which shows a lack of respect toward older adults (Ryan, Hummert, et al., 1995; Williams, 2004). Ryan and colleagues (1986; 1995) developed the Communication Predicament of Aging model to explain this process where communicators such as members of the decision-making constellation may adapt their verbal or nonverbal communication with an older adult based on several stereotypes, including emotional instability, dependency, cognitive decline, and hearing decline (Ryan, et al., 1986; Ryan, Hummert, et al., 1995).

Effectively communicating about falls and health in older adulthood remains a complex

process, but is extremely important for the decision-making process (Ryan, et al., 2006; Ryan, et al., 1986; Ryan, Hummert, et al., 1995; Williams & Nussbaum, 2013).

Decision Making in Older Adulthood. Many researchers have compared older adults' decision-making capacity to the capacity of younger adults. Some researchers have evidence to show that chronological age does not impact decision quality (Hicks Patrick, Steele, & Spencer, 2013). Wood and colleagues (2005b) even found that older people had a capacity to evaluate the wins and losses of a decision more accurately than younger people (Wood, Busemeyer, Kolling, Cox, & Davis, 2005a). Older adults can also make decisions of the same quality as younger adults when they have complete information about the problem, the options, and the associated gains and losses (Zamarian, Sinz, Bonatti, Gamboz, & Delazer, 2008).

Other researchers state that decision-making skills and performance tend to decline with age, thus affecting the quality of the decisions (Bruine de Bruin, Parker, & Fischhoff, 2012; Del Missier, Mäntylä, & Nilsson, 2015). Finucane and colleagues (2005; 2002) report that older adults experience greater comprehension errors and inconsistent preferences than younger adults when making health, finance, and nutrition decisions.

Older adults' motivation to participate in a decision also impacts their decision-making ability (Strough, Bruine de Bruin, & Peters, 2015). Older people are willing to take more risks than younger people when perceiving a positive gain in a decision-making scenario (Mather et al., 2012). In contrast, they would refrain from making a risky decision if they judged their losses to be too important (Mather, et al., 2012).

One possible issue that arises in judging the risks and benefits in older adulthood is that older adults seek less information from external sources when making decisions

compared to younger people (Mata & Nunes, 2010; Mata, Schooler, & Rieskamp, 2007; Mather, 2006), and take more time to process information (Mather, Knight, & McCaffrey, 2005). In addition, when receiving health information, whether positive, negative, or neutral information, older groups tend to remember more positive information than negative information compared to younger groups (Löckenhoff & Carstensen, 2007).

Accessing more information which includes benefits and disadvantages may actually decrease the quality of older adults' decisions; in other words, older adults prefer to have fewer choices or options to choose from when making health care and everyday decision (Mata & Nunes, 2010; Queen, Hess, Ennis, Dowd, & Grünh, 2012). The decision-making performance of older adults also becomes poorer than younger adults when making decisions under ambiguous conditions, such as falls (Zamarian, et al., 2008).

Decision Making after an Older Woman Experiences a Fall. Falls are critical, ambiguous events that can trigger important decision making among older women (Ambrose, et al., 2013; Guttman, 1978). How a fall is interpreted by an older woman can have a big impact on the decisions she makes to regain her health and independence (Guttman, 1978). Falling may bring about feelings of vulnerability and ambiguous dependency of other people, which can challenge an older woman's self-image and identity, possibly increasing her decisional conflict and diminishing her performance when deciding what to do to regain her quality of life (Ballinger & Payne, 2000, 2002; Berlin Hallrup, Albertsson, Bengtsson Tops, Dahlberg, & Grahn, 2009; Dollard, et al., 2012; Shaw, Connelly, & McWilliam, 2014; Zamarian, et al., 2008). Some potential post-

fall decisions an older woman living in a CCRC may make after a fall include limiting her social activities, using assistive technologies (e.g., a life alert or a walker), or moving to another level of care (Clemson, Kendig, Mackenzie, & Browning, 2015; Luz, et al., 2015; Shippee, 2009). Nonetheless, depending on her perception of the fall, it is possible that different intrapersonal factors or personal characteristics may influence her decision-making process. For example, self-rated health, which is a personal assessment of one's own health, can influence the different decisions that she takes after her fall (Kelsey, Procter-Gray, Hannan, & Li, 2012; Lee, 2000; Resnick & Nahm, 2001; Ullmann, et al., 2012). A woman's fall history will also determine how she perceives her new fall as well as her knowledge and preferences of different care options (Gillespie, et al., 2012; Kane & Kane, 2001; Meyeroff, 2010). Health literacy, which is defined as the “degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Institute of Medicine, 2004, p.32), is also crucial in bridging the gap between the individual factors affecting post-fall decision making and the information an older woman receives from her interpersonal sources (Scott, Gazmararian, Williams, & Baker, 2002).

While older adults do not always seek information from external sources when making decisions (Mata, 2007; Mata, et al., 2007; Mather, 2006), it is possible that members of an older woman's decision-making constellation may influence her decisions after a fall by providing specific health-related information (Hesse, et al., 2005; Lambert et al., 2005; Shawler, et al., 2001). In fact, adult children and health care professionals are frequently cited as older women's sources of information (Bowman, Rose, Deimling, Kyriotakis, & O'Toole, 2010; Cicirelli, 2003; Fingerman, 2001; Greene, Adelman,

Charon, & Hoffman, 1986; Hay, Fingerman, & Lefkowitz, 2008; Lee et al., 2013; Shawler, 2006).

Significance of this Research

This study is among the first to examine post-fall decision-making among older women, as well as the first to focus primarily on independent older women living in CCRCs. Based on this literature review, I investigated the complex processes by which older women make decisions about their health and independence after a fall. I explored the types of post-fall decisions older women make and how they make these decisions alone or with members of their decision-making constellation (Shawler, et al., 2001). I investigated whether specific intrapersonal factors such as self-rated health and health literacy influence the types of decisions older women make after a fall (Bennett, Chen, Soroui, & White, 2009; Institute of Medicine, 2004). I also explored the concept of decisional conflict and how it is represented in post-fall decision making, while also comparing decisional conflict between independent older women living in CCRCs and independent older women living in non-institutional homes (O'Connor, 1995). This study provides a greater understanding of how older women make decisions about their recovery, health, and quality of life after a fall. Findings from this study have important implications for research and practice, including education and public health policy for older adults. Most importantly, it has the potential to increase knowledge and understanding of the post-fall decision-making process for older women and their decision-making constellations, which should lead to a variety of benefits including shorter recovery periods after a fall, fewer falls among older women living in CCRCs and

in non-institutional homes, and decreased fall-related medical costs (Centers for Disease Control and Prevention, 2015d; Stevens, et al., 2006).

Previous Work, Studies, and Preparation of Student

Research Activities. During my doctoral studies, I served as project coordinator on two research grants. From January 2011 to December 2013, I was one of two project coordinators on a Health Sciences South Carolina funded grant (PI: Dr. Sei-Hill Kim; Co-PIs: Dr. Andrea Tanner and Dr. Daniela B. Friedman) to better understand South Carolinians' perceptions, knowledge, and attitudes towards clinical trials. From August 2013 to August 2015, I was one of four project coordinators on a Knight Foundation funded grant (PI: Dr. Andrea Tanner; Co-PI: Dr. Daniela B. Friedman) to assess and improve the knowledge and communication of the Affordable Care Act (ACA) with Richland County residents in South Carolina. Through these two main positions, I gained relevant experience conducting both qualitative and quantitative research, which helped me conduct my own mixed methods dissertation.

In terms of qualitative research experience, I helped to develop focus group protocols and supporting documents (e.g., information letter, consent form, demographic survey, recruitment flyer, etc.). I organized and facilitated cognitive interviews, 19 focus group discussions and eight telephone interviews with people from both urban and rural areas of the state for the clinical trials project, as well as 12 focus groups with Whites, African Americans and Latinos in English and Spanish, and four more summer focus groups for the ACA project. I helped to organize education sessions where my colleagues delivered an education program on the ACA. I also assisted with data collection and analysis. I have substantial experience using QSR NVivo 10 (QSR International Pty Ltd,

2012) as a software to help organize data for analysis and am knowledgeable with code books, thematic analysis, and grounded theory approach to analysis.

With the clinical trials project, I gained relevant quantitative experience assisting in the development of an online survey for principal investigators of clinical trials as well as the development and pre-testing of a telephone survey for the general population in South Carolina. I worked on secondary data analysis using Medicaid, State Health Plan, and US Census data to find potentially eligible clinical trials participants in the state, and used both parametric and nonparametric statistics to analyze the data. I co-developed a code book and conducted a quantitative content analysis of clinical trials education and recruitment materials throughout the state. I also helped conduct an exhaustive media analysis of news articles related to clinical trials.

With the ACA project, I assisted in developing a randomized telephone survey with 509 Richland County residents on their knowledge and communication of the ACA. I helped to develop a pretest and posttest survey that would accompany the ACA education program, which included a test of functional health literacy in older adults (TOFHLLA), as well as an evaluation of the education program. I am familiar with IBM SPSS Statistics 22 (IBM Corp., 2013) and Stata 11 (StataCorp LP, 2009) to run bivariate and multivariate analyses.

I contributed to the productivity of both research teams by helping to draft academic manuscripts and by presenting our study findings at local, state, national, and international conferences. To date, for the clinical trials project, we have nine publications (Bergeron, Foster, Friedman, Tanner, & Kim, 2013; Friedman, Bergeron, Foster, Tanner, & Kim, 2013; Friedman, Foster, Bergeron, Tanner, & Kim, 2015;

Friedman et al., 2014; Friedman, Tanner, Kim, Bergeron, & Foster, 2014; Kim, Tanner, Friedman, Foster, & Bergeron, 2015; Kim, Tanner, Friedman, Foster, & Bergeron, 2014; Tanner, Kim, Friedman, Foster, & Bergeron, 2015a, 2015b), and one article in review (Tanner et al., In review). We also participated in three invited presentations and 10 conference presentations including at the 2012 and 2013 Association for Education in Journalism and Mass Communication Conference. For the ACA project, we have one article in press (Tanner et al., In press) and two articles in review (Bergeron et al., In review; Friedman et al., In review); we were invited to present our study findings twice and made 10 other conference presentations, including at the 2015 National Conference on Health Communication, Marketing and Media, the 2014 Association for Education in Journalism and Mass Communication Conference, and the 2014 American Public Health Association Annual Meeting.

Relevant Coursework. I took both quantitative and qualitative courses that enabled me to better understand and analyze my dissertation data. In EDRM 711, Educational Statistics II, I learned how to conduct hierarchical regressions, path analyses, and analyses of variance. In HPEB 810, Applied Measurement in Health Education Research, I developed scales and assessed their reliability and validity. In HPEB 792, Theory Driven Data Analysis, I developed research questions and hypotheses and conducted multivariate analyses to answer my research questions. In HPEB 715, Qualitative Research in Public Health, I learned about the multiple steps involved in qualitative research. In JOUR 808, Communication Research, I conducted observations and interviews on the topic of health communication in a retirement community. In HSPM 764, Long Term Care Administration, I visited and learned about different

CCRCs and programs for older adults in the Columbia area. In HPEB 802, Implementation and Monitoring of Health Promotion Programs, I conducted a process evaluation of a triathlon training program for older adults at a retirement community in South Carolina using observations, interviews, and focus groups and monitored the triathlon training program for six weeks.

From January to March 2013, I completed a practicum at the Public Health Agency of Canada in Emergency and Risk Communications where I interviewed both public health leaders and experts in gerontology to learn about the different challenges and opportunities in public health and aging. At the same time, I worked on developing a tool to evaluate risk messages. My advisor and I presented this tool at two international conferences and also drafted a manuscript to describe the development process and the importance of evaluating disaster risk messages (Bergeron & Friedman, 2015).

Other Aging-Related Work Experience. In April 2012, I participated in a CDC Healthy Aging Research Network community wayfinding project where I reviewed, coded, and provided feedback on a total of 27 articles related to technology for mobility, navigation, and falls prevention among older adults. Through this project, I further developed my analytical skills and got the opportunity to collaborate with a national multidisciplinary team of experts in aging.

From March to November 2014, I worked with the University of South Carolina's Office for the Study of Aging (OSA) to develop a module on falls prevention and post-fall decision making for the HOMECARE+ Specialist Training program. Along with a staff member at the OSA, we developed a presentation on falls, fall risk factors, fall prevention interventions and we also included some preliminary results from my

dissertation on the key decisions older women make after experiencing a fall. We developed a training module, a pre-test, a post-test, an answer key, a training log, and handouts. The OSA taught this module to the home care agencies who then trained their direct care workers about falls.

From August to October 2014, I worked at the World Health Organization Regional Office for Europe in Copenhagen, Denmark in the Healthy Ageing, Disability, and Long-Term Care Unit. During my internship, I conducted a literature review on age-friendly practices and dementia-friendly communities. I assisted in the development and strategic planning of the Age-Friendly Environments in Europe project. I also collaborated with key players in aging research including the University of Manchester, AARP, Age Friendly Ireland, and Alzheimer Europe.

From November 2014 to August 2015, I worked on a contract with AARP International to find and describe U.S. and international age-friendly best practices representing the eight domains of livability. I interviewed more than 20 stakeholders about their best practices, including experts in Taiwan, the United Kingdom, France, and Australia, and wrote a report to encourage other cities to follow their examples. The case studies are published online on the AARP website as well as in the *2015 Age-Friendly Report: Inspiring Communities* (Turner, Stanton, & Bergeron, 2015).

Implications of Research for Candidate. My dissertation research has important research, practice, and policy implications for older women and their decision-making constellation to help manage and prevent future falls. This research also has had positive consequences in my life and my future research career. Since my dissertation proposal defense in November 2013, I have gained an incredible amount of research experience by

developing and revising all of my study protocols, pilot testing my interview guides and surveys, building community partnerships with CCRCs and aging-related agencies throughout the state of South Carolina to recruit study participants, meeting with over 150 participants one by one to discuss their experiences with falls, entering the data, cleaning the data, working with my committee members to analyze both qualitative and quantitative data, writing my three dissertation manuscripts, writing this final dissertation document, and sharing my research findings with study participants, CCRCs, and other community partners. I believe to have greatly developed my research skills with primary data collection and analysis. Most importantly, I developed a true passion for research in healthy aging and for the population with which I worked. I hope to continue conducting research in aging and health communication and working toward building evidence-based policies and practices to improve and maintain the health of older adults.

CHAPTER 3

RESEARCH DESIGN AND METHODS

Overview of Research Design

To better understand decision making after a fall, I used a two-phase mixed method study design (Creswell, 2007) that involved: (1) data from individual, in-depth, semi-structured interviews with *primary informants*, which were independent older women living in CCRCs who had experienced a fall within the previous six months, along with *secondary informants*, which were individuals the women identified as their main sources of information in their post-fall decision-making processes; and (2) data from in-person paper-pencil exploratory fall assessment and decision-making surveys with the *primary informants*, which were independent older women living independently either in CCRCs and non-institutional homes, who had experienced a fall within the previous 12 months. I obtained approval for all study protocols and documents from the University of South Carolina's Institutional Review Board (ID: Pro00030873) prior to starting data collection. I present the research methods in these two phases to address the study's three specific aims:

Phase 1: Qualitative Study

Aim 1. To explore the interpretations and personal meanings associated with falls and post-fall decisions of older women living in CCRCs.

Aim 2. To examine how specific interpersonal factors and information sources relate to post-fall decision making among older women living in CCRCs.

Phase 2: Quantitative Study

Aim 3. To examine how specific intrapersonal factors relate to post-fall decision making among older women living in CCRCs and in non-institutional homes.

Conceptual Framework

This study was guided by the Disablement Process Model, as illustrated in Figure 3.1 (Jette, 2006, 2009; Verbrugge & Jette, 1994). This model describes the process through which a chronic illness can bring a loss of independence and disability.

Specifically, Verbrugge and Jette (1994) suggest that the disablement process occurs through the main pathway starting from pathology, to impairment, to functional limitations, and to disability. Similar to a chronic disease, I argue that a fall can also result in such loss of independence (Cumming, Salkeld, Thomas, & Szonyi, 2000; Yardley & Smith, 2002). I therefore adapted the Disablement Process Model to focus, from left to right, on how a fall (or the pathology in Verbrugge and Jette's case) triggers decision making that is influenced by several factors, which leads to decisions being made and specific health outcomes.

In the Disablement Process Model, two types of environmental factors accelerate or slow the disablement process: intrapersonal and interpersonal factors. In our adapted version of the model, intrapersonal factors and interpersonal factors also play a role in the decision-making process. Intrapersonal factors include self-rated health (Resnick & Nahm, 2001), history of falls (Gillespie et al., 2012), severity of falls (Sterling, O'Connor, & Bonadies, 2001; Tinetti & Williams, 1997; Tousignant et al., 2013), health literacy (Parker & Ratzan, 2010; Ratzan & Parker, 2006; Scott, et al., 2002), and familiarity and openness to care options (Department of Health and Human Services,

2011, n.d.; National Care Planning Council, 2013). For example, an older woman's familiarity with assisted living may impact the decisions and changes she makes after her fall (Meyeroff, 2010).

Interpersonal factors and information sources refer to the decision-making constellation and other media sources which can influence the decision-making process (Barry & Edgman-Levitan, 2012; Jones, 1997; Shawler, et al., 2001; Waldron, Gitelson, Kelley, et al., 2005). For example, an older woman may strongly consider the advice she receives from her adult child in her post-fall decisions. Other information sources such as news articles, radio shows, television advertisements, the internet, and brochures may also impact her decision-making process (Briss et al., 2004; Hesse, et al., 2005; Passalacqua et al., 2004; Stacey et al., 2014).

The right hand side of the conceptual framework in Figure 3.1 points to how this decision-making process brings specific post-fall decisions and outcomes of those decisions, which impact the older women's health, independence, and quality of life. Some post-fall decisions may include using a walker, moving to another level of care within the CCRC, and engaging in physical activity. These decisions may then result in specific health outcomes after the fall, including increased stability and confidence when walking (Bateni & Maki, 2005; Katrin, Matthias, Winfried, & Lutz, 2009), increased isolation (Aoyama, Suzuki, Onishi, & Kuzuya, 2011), or increased disability (Deshpande et al., 2008).

Setting

I conducted individual, in-depth, semi-structured interviews to address Aims 1 and 2 with a purposive sample of older women residing in independent living in one of

two CCRCs located in the Midlands region of South Carolina. Both CCRCs were equipped with amenities and services, including a fitness center, large dining room, beauty salon, barber shop, postal center, gift shop, religious services, concierge services, home care services, and physical therapy, among others. I used pseudonyms to protect the identity of the facilities and participants.

Happy Days Retirement Community was a relatively small religious-affiliated CCRC in the Columbia area. At the time of data collection, it had 123 residents of which 85 residents lived independently in the CCRC's cottages and apartments. Sixty percent of all independent residents were women, and residents reported at least one fall per week. The average age of female residents was 86 years old. Nearly all residents were Caucasian, had at least an undergraduate college degree, and were considered as coming from an upper middle class (personal communication, August 15, 2013).

Bright Side Retirement Community was a larger religious-affiliated CCRC in the Columbia area. It had close to 400 residents at the time of data collection, of which 185 resided in independent living in cottages and apartments. Ninety percent of all independent residents were women, and the average age was 79 years old. *Bright Side* had many accounts of reported falls, but also had large numbers of unreported falls. Similar to *Happy Days*, most residents were Caucasian, had at least an undergraduate education, and came from an upper middle class (personal communication, November 7, 2012).

I also conducted individual in-depth interviews with secondary informants, which were individuals the older women had identified as being involved in their post-fall decision-making processes. These interviews were conducted in person at the secondary

informants' office, home, and at the CCRCs, while two of these interviews were conducted by telephone.

For Aim 3, I administered the in person, paper-pencil exploratory survey to 65 older women living independently in 10 different CCRCs across the state. I worked with the Executive Director of Leading Age South Carolina who served as our liaison to establish partnerships with these different settings. I also administered the survey to another sample of 65 older women living independently in non-institutional homes. I administered the survey to participants at various locations across the state including senior centers, senior apartment buildings, libraries, coffee shops, and in their homes. I conducted 15 out of 65 surveys by telephone.

Phase 1 - Aims 1 and 2

Sample and Recruitment Procedures.

Primary informants. From December 2013 to June 2014, I recruited a purposive sample of 17 older women living independently in CCRCs. The inclusion criteria were as follows: female gender, 65 or older, speaks and reads English, currently living independently in one of the two designated CCRCs, experienced a fall within the last six months and suffered at least a minor injury such as a wound, bruise, or cut based on self-report, which caused her to limit her regular activities for at least one day (Stevens, Mack, Paulozzi, & Ballesteros, 2008). I interviewed women who had suffered one unique fall as well as those who had experienced multiple falls within the last six months.

To recruit participants, I first posted recruitment flyers and made formal presentations at the two CCRCs. See Appendix A for the recruitment flyer for the interviews with the primary informants. I collaborated with a staff member at *Bright Side*,

who approached potential participants, explained the study, informally assessed their cognition and memory, and ensured that they met our eligibility criteria. She then obtained their approval before sharing their contact information with us so I could schedule the interview.

At *Happy Days*, I obtained permission from the administrators to directly approach and inform older female residents about the study while they waited to go eat in the dining area. I recruited three participants using this approach as well as two more participants through informal snowball sampling.

Secondary informants. For Aim 2 where I conducted individual, in-depth, semi-structured interviews with secondary informants, I asked the primary informants to identify their top three main sources of information when they were making decisions after their fall. I then asked the primary informants to provide me with the contact information for these individuals who knew the most about the women's indicator fall, i.e., the most significant fall she had experienced within the previous six months and the one she discussed during the interview. Two participants reported not receiving any help in making decisions after their falls. Four participants refused to provide me with the contact information for their sources of information. I interviewed 11 secondary informants: the women's husbands, adult children, health professionals, and CCRC staff. They all met our eligibility criteria of speaking English, living in South Carolina, and having been involved in the women's post-fall decision-making process.

Data Collection Procedures.

Interviews with primary informants. To address Aims 1 and 2, I used an open-ended, semi-structured interview guide to conduct individual, in-depth interviews with

the primary informants. See Appendix B for the interview guide with the primary informants. I obtained feedback from the two CCRCs on the wording, format, and length of the interview guide; I also pilot tested the interview questions with a community-dwelling older woman who had recently experienced a fall and made minor adjustments based on her feedback to improve the receptivity and the clarity of the questions prior to data collection. I used a digital recorder and a voice recorder on a cellular phone to capture the content of all interviews. I also recorded field notes after each interview.

The interview questions touched on an older woman's experience with and after a fall. To frame the discussion, I first asked the participant to select and discuss an "indicator" fall, i.e., a fall that was either the most recent or the most significant for her because of the fall experience or the consequences of the fall (e.g., injury) that occurred in the previous six months. The rest of the interview questions touched on this indicator fall. Two questions asked the participant to talk about this fall in detail, with nine different prompts to fully contextualize the fall, as well as to discuss "How did you feel about this fall?". These questions are based on Roe and colleagues (2008)'s study on post-fall experiences. The second part of the interview then focused on the primary informant's decisions and changes she made after her indicator fall. Four interview questions directly asked her the types of decisions she made, the changes she made in her life and/or environment, other possible outcomes that resulted from these decisions, and finally how she felt about falling after making these changes. The third part of the interview was specific to Aim 2 of the study and asked the participant a series of ten questions regarding potential information sources and interpersonal factors that may have influenced her post-fall decision making after this indicator fall (e.g., "what kind of

help/advice did he/she give you?”). These questions were primarily based on the work by Shawler, Rowles, and High (2001) on the decision-making constellation as well as Cornwell and colleagues (2009)’s research on social networks. I also asked the primary informant her opinion about how these interpersonal sources influenced her post-fall decisions, and how she felt about her decisions and the changes she made in her life after her indicator fall. At the end of the interview, I asked the participant to provide me with the contact information of the top three individuals she mentioned were involved in her post-fall decision-making process.

I conducted all interviews with the primary informants in person to minimize the impact of hearing loss among this older population as well as to establish a better, more trusting relationship with the participant. All participants provided their verbal and written consent to complete the interview prior to data collection. See Appendix C for the information letter and consent form for the interviews with the primary informants. The interviews lasted between 30 minutes and 2.5 hours, with an average length of 60 minutes. All participants also completed a 10-item demographic survey at the end of the interview. The survey asked for participants' year of birth, race, marital status, education, current living situation, years living in the CCRC, date of indicator fall, type of injuries incurred during indicator fall, sources of information in post-fall decision-making process, and total number of falls in the past six months. See Appendix D for the demographic survey administered to the primary informants. Each participant received a \$30 cash incentive for her time and participation in the research.

Interviews with secondary informants. To address Aim 2, I used a second semi-structured interview guide for the individual, in-depth interviews with the secondary

informants. See Appendix E for the interview guide for the interviews with the secondary informants. I pilot tested the interview questions with the spouse of a community-dwelling older woman who had recently experienced a fall, and made minor adjustments to the format and wording based on his feedback. I recorded all the interviews with a digital recorder and a voice recorder on a cellular phone. I also took field notes after each interview.

The interview questions touched on the secondary informant's involvement in the older woman's post-fall decision making. Precisely, I asked the secondary informant to describe his or her relation and relationship with the participant, to explain what he or she knows about the participant's indicator fall, i.e., "Please tell me what you know about this fall", as well describe the changes and the decisions the older woman made after her indicator fall. I then asked a series of seven questions to better understand the secondary informant's involvement in the post-fall decision-making process. For example, I asked the secondary informant, "How were you involved in the decisions that she made after her fall?", "What type of information, if any, did you provide her after her fall?", "What type of advice, if any, did you provide her after her fall?", and "How did [CCRC Resident's Name] respond to the information or advice you gave her?". I asked the secondary informant if he or she knew of any other factors that may have contributed to the woman's post-fall decisions. I concluded the interview by asking the secondary informant to rate his or her own feedback in the decision-making process and give his or her opinion of the final decision made by the participant.

I conducted most interviews with the secondary informants in person and two interviews by telephone with secondary informants living in a remote area of the state.

All secondary informants provided their verbal or written consent to taking part in the study prior to data collection. See Appendix F for the information letter and consent form for the interviews with the secondary informants. The interviews lasted between 20 minutes and 1.5 hours with an average of 40 minutes. At the end of the interview, I asked all secondary informants to complete a 9-item demographic survey to obtain information on their age, race, marital status, education, income, relationship to primary informant, frequency of communication with primary informant, perceived importance in the post-fall decision-making process, and perceived involvement in the post-fall decision-making process. See Appendix G for the demographic survey administered to the secondary informants. To thank participants for their time and participation in the research, I gave each in-person interview participant a \$30 cash incentive and each telephone interview participant a \$30 Target gift card. Table 3.1 provides a summary of the interview domains and questions for the primary and secondary informants.

Data Analysis.

Qualitative data. I sent all the audio-recorded interviews to be professionally transcribed by Verbal Ink Transcription Services. I provided the interview guides and guidelines on format and content to help the professionals transcribe the 28 interviews. I removed all identifying information from the transcripts and attributed a pseudonym to each interviewee to protect her or his identity. Before, during, and after analysis, I kept all the data, transcripts, demographic surveys, audio files, and consent forms confidential and locked away in a filing cabinet in a secure location.

Using grounded theory coding techniques (Strauss & Corbin, 1998; Thomas & Harden, 2008), two of my committee members and I started the analysis by

independently and inductively coding by hand one individual transcript using open coding. We coded the meaning and content of each line of text (Thomas & Harden, 2008) and identified the main concepts and dimensions (Strauss & Corbin, 1998). We met to discuss the codes and the meaning of each code. Following this meeting, we continued the iterative open coding process with three other transcripts. During this process, each of us created coding and category summaries, which we incorporated into an evolving coding scheme.

After this initial analysis, I uploaded all the transcripts and field notes into NVivo 10 (QSR International Pty Ltd, 2012), a qualitative software that helps to organize, analyze, and interpret data. I entered our initial analyses into NVivo and continued this open coding process while also creating summaries of codes and categories that were emerging. Together, the three of us revisited the summaries of codes and categories and tried to identify similarities and differences. To more accurately explore the post-fall decision-making process, we used a constant comparison method to examine codes within each interview and across sets of interviews, by dyad comparing the interviews with the primary and secondary informants, and across all interviews (Silverman, 2013). We also compared the transcripts, reviewing the previous analyses, recoding based on new information, and revising and comparing the data based on new codes and new categories found in the transcripts. We then grouped similar codes, made comparisons, and identified broader categories. We continued with axial coding where we reviewed the transcripts to identify specific attributes, dimensions, and variations within and across each category (Strauss & Corbin, 1998). This led us to identify the final broad themes. We stopped the analyses when multiple revisions did not yield distinctly different

categories and themes, which led us to believe we had reached data saturation (Morse, Barrett, Mayan, Olson, & Spiers, 2008; Patton, 2002).

Quantitative data. To analyze the participants' demographics survey data, I started a new data set in IBM SPSS Statistics 22.0 (IBM Corp., 2013), created all the variables, and entered all of the participants' responses from the demographic surveys. I then verified all the entries, looking for errors and missing data. After the data were cleaned, I ran nonparametric frequencies and percentages.

Phase 2 - Aim 3

Sample and Recruitment Procedures.

Primary informants. From January to March 2015, I recruited 65 older women residing in different CCRCs across the state, as well as 65 older women living in non-institutional homes to complete our exploratory survey. The inclusion criteria for Aim 3 were as follows: female gender, 65 or older, speaks and reads English, currently living independently in a CCRC or in a non-institutional home, experienced a fall within the previous 12 months and suffered at least a minor injury such as a wound, bruise, or cut based on self-report, which caused her to limit her regular activities for at least one day (Stevens, et al., 2008). I recruited women who had experienced one unique fall or who had experienced multiple falls within the last 12 months.

To recruit 65 CCRC participants, I first approached *Bright Side*, with whom I had worked for Aims 1 and 2 of the study. *Bright Side* collaborators made a list of all potential participants who met the eligibility criteria, and contacted them on our behalf to assess their interest in completing a brief survey about their fall(s). I invited all interested and eligible participants to group survey sessions where multiple participants could

complete the paper-pencil survey at the same time. Alternatively, I met with participants in their home or in a public area inside the CCRC to conduct the survey.

To recruit participants from other settings, I used a two-phase recruitment strategy where I first focused on retaining CCRCs followed by recruiting participants. I contacted all CCRCs in the state by email or through their websites to tell them about the study. The Executive Director of Leading Age South Carolina then helped me establish a connection with the CCRCs by sending an email to all administrators to confirm the legitimacy of the study and to encourage CCRCs to participate. Staff from 12 different retirement communities responded to the call for action, and two CCRCs declined to participate after obtaining more information. Staff collaborators in the CCRCs helped me recruit participants by making lists of female residents currently in independent living who had experienced a fall in the last 12 months, checking their eligibility based on our study's inclusion criteria, and contacting them directly to assess their interest in taking the survey. Other CCRCs posted our recruitment flyer on their bulletin boards and added the phone number of a CCRC staff who would provide more information about the study. See Appendix H for the recruitment flyer for the surveys with the primary informants living in CCRCs. The CCRCs then provided me with the participants' names and phone numbers whom I contacted to reassess their eligibility and to set up a time to complete the survey individually or as part of a group session. I also recruited a few participants through word of mouth.

To recruit 65 non-CCRC participants, I distributed the recruitment flyer in senior centers, senior apartment buildings, federally qualified health centers, geriatricians' offices, physical therapy clinics, County Councils on Aging, and Area Agencies on

Aging across the state. See Appendix I for the two recruitment flyers for the surveys with the primary informants living in non-institutional homes. I collaborated with staff of a regional home health agency, who contacted all of its female clients to tell them about the study and assess their eligibility. Staff at the home health agency then provided me with the eligible participants' information so I could contact them directly to set up a time to complete the survey. I made brief informal presentations to promote the study at an assistive technology conference, at local falls prevention program sessions, and at senior group fitness classes. I also shared our recruitment flyer with senior participants of other academic studies at our university. I promoted the study through the state's office on aging website, a local radio show for older adults, social media including Twitter and Facebook, as well as electronic mailing lists of non-profit organizations targeting older adults, church groups, neighborhood associations, the state respite coalition, the state public health association, and through word of mouth.

Data Collection Procedures.

Surveys with primary informants. To address Aim 3, I developed and administered an exploratory survey to 65 independent older women living in CCRCs and 65 independent older women living in non-institutional homes across the state who experienced a fall within the previous 12 months. I conducted the majority of the surveys in person, but administered 16 out of 130 surveys by telephone due to the participant's remote location. I developed the survey based on Phase 1 of this research (i.e., post-fall decisions women made) as well as on the falls prevention literature (Centers for Disease Control and Prevention, 2015a; Lord, et al., 2007; Sherrington, 2008). I also pilot tested the survey with three independent older women who had experienced a fall within the

previous year and made minor adjustments to increase readability and clarity of the items prior to data collection. See Appendix J for the exploratory survey with the primary informants. All survey participants read an information letter and signed a consent form before taking the survey. See Appendix K for the information letter and consent form for the exploratory survey with the primary informants. The survey took on average 20 minutes to complete. In-person survey participants received a \$15 cash incentive and telephone survey participants received a \$15 gift card from Target, Walmart, Piggly Wiggly or Publix that I mailed to their home address in compensation for their time and contribution to the research. I kept all the data, surveys, and consent forms anonymous, confidential, and locked away in a filing cabinet in a secure location.

Measures and specification of variables. This survey was divided into six sections. In section A, Health, I assessed two of the five independent variables: self-rated health and health literacy. In section B, I touched on the participant's history and severity of falls. In section C, I examined post-fall changes. In section D, I examined the dependent variable: decision making. In section E, I assessed familiarity and openness to care options. In Section F, I included demographic questions.

Section A: Health. I measured *self-rated health* using a single item from the revised 12-item Short-Form Health Survey (SF-12) that was found to be a reliable and valid measure of health status in independent living older adults (Resnick & Nahm, 2001). The one item is "In general, would you say your health is...Excellent, Very Good, Good, Fair, or Poor?"

I also used one single item to measure a component of older women's health literacy. The *Single Item Literacy Screener* (SILS) asks, "How often do you need to have

someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy” (Morris, MacLean, Chew, & Littenberg, 2006). Responses ranged from Never, Rarely, Sometimes, Often, and Always. This helped determine older women’s self-reported health literacy. Health literacy has been associated with knowledge of diseases (Gazmararian, Williams, Peel, & Baker, 2003), screening and prevention measures such as getting a Pap smear or a mammogram (Scott, et al., 2002), risk of hospitalization (Baker et al., 2002) and other health behaviors. With this question, I also wanted to assess whether health literacy is related to falls and post-fall decision making among older women.

Section B: Falls. I used two items to measure *history and severity of falls*. The first item “How often have you fallen in the past 12 months?” offered the following response options: “Once”, “A few times in the year”, “Once every couple of months”, “Once a month”, “A few times a month, but not every week”, and “Every week” (Gillespie, et al., 2012). The second item asked “Considering all of your falls in the past 12 months, how severe were your falls?” with responses on a 5-point Likert scale ranging from “Very minor” to “Very severe.” Participants answered this question by comparing their falls to falls they had in the past as well as falls their peers from the same age group had experienced. This last item was adapted from previous studies assessing the severity of previous falls (Sterling, et al., 2001; Tinetti & Williams, 1997; Tousignant, et al., 2013).

Section C: Changes. I asked participants to place a check mark beside any of the 34 items listing changes they may have made after experiencing the fall(s) they had in the past 12 months, using the following item: “Which changes did you make after

experiencing a fall?” These included items like: going to a rehabilitation facility, taking pain medication, getting new shoes, using a walker, wearing an emergency button, etc. This list of changes was taken from fall prevention recommendations (Centers for Disease Control and Prevention, 2015a; Lord, et al., 2007; Sherrington, 2008) as well as from the results of Phase 1. Survey participants also had the opportunity to add one or more post-fall changes that was not on the list under “Other? Specify.” The follow-up question asked participants to go through the previous question and to select and rank in order of importance the top three changes they made after their fall(s).

Section E: Decision making. In Section 5 of the survey, I assessed our dependent variable of decision making. I used the *Decisional Conflict Scale (DCS)* (O'Connor, 1995) to assess uncertainty in making health-related decisions, as well as perceived effective decision making among older women. The DCS is a 16-item instrument which has been found to be a valid and reliable measure, with a Cronbach's alpha between 0.78 and 0.92. However, I only used 8 items from this scale, four of which consisted a subscale with a Cronbach's alpha of 0.82. These items included, on a 5-point Likert scale ranging from “Strongly disagree” to “Strongly agree”: “The decision to make this change was hard for me to make”, “I felt I needed more advice and information before making this decision”, “I felt pressure from others in making this decision”, and “I had the right amount of support from others in making this decision”. I also used four items measuring the subscale of perceived effective decision making, including “I feel I have made an informed choice”, “My decision shows what is most important for me”, “I expect to stick with this decision and change”, “I am satisfied with my decision to make this change” (Molenaar et al., 2000; O'Connor, 1995; O'Connor, et al., 1998).

To complement this last dimension, I used one item from the *Satisfaction with Decision Scale* (Holmes-Rovner et al., 1996), a 6-item scale which has good reliability with a Cronbach's alpha of 0.88. On a 5-point Likert scale ranging from "Strongly disagree" to "Strongly agree", I asked participants to answer this item: "The decision I made to make this change was the best decision possible for me personally" (Holmes-Rovner, et al., 1996; Lantz et al., 2005; Molenaar, et al., 2000).

Section E: Care options. I examined familiarity with care options by assessing the primary informants' awareness of the following three options (Department of Health and Human Services, 2011, n.d.; National Care Planning Council, 2013), ranging on a scale from 1 to 5, where 1 is "I am not at all familiar" and 5 is "I am very familiar": adult day care, assisted living, nursing home. I provided a simple definition for each care option.

Openness to care options was assessed using the same items, but by changing the question slightly to the following: "Please think about the fall(s) that you experienced in the past year. Indicate how open you would be to accepting the following care options if you needed assistance after your fall." These items used a 3-point scale, ranging from 1- "I am not at all open," 2- "I am somewhat open," and 3- "I am open." The purpose of looking at these care options was to assess how their familiarity and openness may impact the primary informants' post-fall decisions (Meyeroff, 2010).

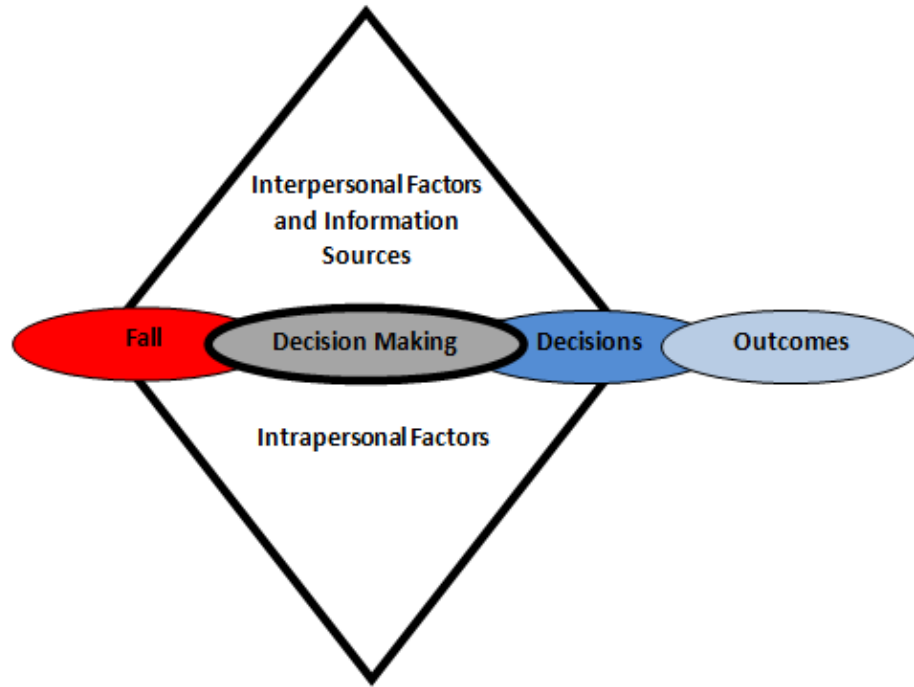
Section F: Demographics. I included nine demographic questions at the end of the survey. These items captured participants' age, race, marital status, education, living situation (i.e., alone, with spouse/partner, other), living in a CCRC (yes/no), time living in a CCRC, whether they were interviewed about their fall in the first phase of the study, and how they heard about the study.

Table 3.2 provides a summary of the variables and measures for the surveys with the primary informants. All variables and measures relate to the constructs of intrapersonal factors and decision making as presented in the conceptual framework.

Data Analysis

Data Analysis – Quantitative Data.

I manually entered the data into IBM SPSS Statistics 22.0 (IBM Corp., 2013), a statistical software program. I cleaned the quantitative data by checking for missing data and entry errors using the completed questionnaires. I obtained descriptive statistics by running nonparametric frequencies and percentages. I conducted bivariate analyses using cross tabulations, correlations, and one-way analyses of variance. I then ran simple and multiple OLS regression to test the relationship between post-fall categories, familiarity with assisted living and nursing home, health literacy, and decisional conflict. Significance was considered at a 95% confidence level and a p -value less than .05 ($p < .05$).



*Adapted from Verbrugge and Jette (1994)'s Disablement Process Model

Figure 3.1: Older Women's Post-Fall Decision-Making Processes and Outcomes*

Table 3.1: Summary of Interview Domains and Questions

Research question	Conceptual framework construct	Sample interview questions
RQ1: What meanings do older women residing in CCRCs associate with their experience of a fall?	Fall	“Tell me about this fall.” “How did you feel after this fall?”
RQ2: What decisions do older women residing in CCRCs make after a fall and what are the outcomes of those decisions?	Decisions Outcomes	“What type of decisions did you make after your fall regarding your health?” “What changes did you have to make in your life and/or environment to respond to these decisions?”
RQ3: Who or what do older women residing in CCRCs identify as their main sources of information when making post-fall decisions?	Interpersonal factors and external sources	“What type of information, if any, did you seek in order to decide to [add decision mentioned]?” “Who, if anybody, helped you make this decision?”
RQ4: What type of information and advice do these sources provide?	Interpersonal factors and external sources Decision making	“What type of information did he/she give you after your fall?” “What kind of help/advice did he/she give you?”
RQ5: How do older women residing in CCRCs assess the quality, credibility, and trustworthiness of these sources when making post-fall decisions?	Interpersonal factors and external sources Decision making Decisions	“Among all these contacts, who would you say provided you with the best advice? Why?” “Among all these contacts, which ones would you say are credible sources of information? Why?” “Among these people, which ones did you trust the most? Why?”
RQ6: If a person is identified as the older	Interpersonal factors and external sources	“How were you involved in the decisions that she made

<p>woman's main source of information, how does this person view his/her role in the older woman's post-fall decision making?</p>	<p>Decision making</p> <p>Decisions</p> <p>Outcomes</p>	<p>after her fall?"</p> <p>"In your opinion, how important was your feedback in her decision-making process?"</p> <p>"What was [CCRC Resident's Name]'s final decision?"</p>
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Table 3.2: Summary of Variables and Measures for Surveys with Primary Informants

Research question	Variable	Scale	Sample items	Response options
RQ7: How are older women's self-rated health, history of falls, severity of falls, and health literacy associated with their post-fall decision making?	Self-rated health	Short-Form Health Survey (SF-12) (Resnick & Nahm, 2001)	"In general, would you say your health is...?"	5-point Likert scale: "Excellent" to "Poor"
	Health literacy	Single Item Literacy Screener (Morris, et al., 2006)	"How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"	5-point Likert scale: "Never" to "Always"
RQ7: How are older women's self-rated health, history of falls, severity of falls, and health literacy associated with their post-fall decision making?	History of falls	Bergeron based on literature from Gillespie et al. (2012)	"How often have you fallen in the past year?"	6-point Likert scale from "Once" to "Every week"
RQ7: How are older women's self-rated health, history of falls, severity of falls, and health literacy associated with their post-fall decision making?	Severity of falls	Bergeron based on literature from Sterling et al. (2001), Tinetti & Williams (1997) and Tousignant et al. (2013)	"Considering all of your falls in the past year, how severe were your fall(s)?"	5-point Likert scale: "Very minor" to "Very severe"

RQ7/RQ8/RQ9 RQ9: How are older women's post-fall decisions associated with decisional conflict?	Post-fall changes	Bergeron and falls prevention literature (Centers for Disease Control and Prevention, 2015a; Lord, et al., 2007; Sherrington, 2008)	“Which changes did you make after experiencing a fall?” “From the list in the previous three pages (Question C1), please write below your three most important changes.”	Place a check mark if you made the change listed.
RQ7/RQ8/RQ9 RQ9: How are older women's post-fall decisions associated with decisional conflict?	Decision making	Decisional Conflict Scale (DCS) (O'Connor, 1995)	“I felt pressure from others in making this decision.”	5-point Likert scale: “Strongly disagree” to “Strongly agree”
		Satisfaction with Decision Scale (Holmes-Rovner, et al., 1996)	“The decision I made to make this change was the best decision possible for me personally.”	5-point Likert scale: “Strongly disagree” to “Strongly agree”
RQ8: How are older women's familiarity of care options and openness to care options associated with their post-fall decision making?	Familiarity with care options	Bergeron based on information from the Department and Health and Human Services (2011, n.d.) and National Care Planning Council (2013)	“How familiar are you with... adult day care? assisted living?”	5-point Likert scale: “Not at all familiar” to “Very familiar”
RQ8: How are older women's familiarity of care options and openness to care options associated with their post-fall decision	Openness to care options	Bergeron based on information from the Department and Health and Human Services (2011, n.d.) and National Care	“How open would you be to accepting... adult day care? assisted living?”	3-point scale: “Not at all open”, “Somewhat open”, “Open”

making?		Planning Council (2013)		
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CHAPTER 4

RESULTS

4.1 Manuscript 1

Older Women's Responses and Decisions after a Fall: The Work of Getting "Back to Normal"¹

¹ Bergeron, CD, Friedman, DB, Messias, DKH, Spencer, SM, & Miller, SC. Submitted to *Health Care for Women International*.

Abstract

This exploratory descriptive research examined post-fall responses and decisions among 17 older women who had experienced a fall within the previous six months. Falls were *unexpected, sudden events* that heightened these women's awareness of their physical, emotional, spiritual, and social independence. Interviewees reported the added work of "getting back to normal" which entailed *assessing personal physical and emotional needs; seeking and obtaining assistance and spiritual support; avoiding specific people, objects, and places; and planning ahead*. Consideration of older women's post-fall responses and decisions should be incorporated into falls prevention and management programs, services, and clinical recommendations.

Key words: Older Women; Falls; Decision Making; Continuing Care Retirement Communities; Qualitative Research

Introduction

Falls among the elderly are a significant global public health issue, impacting the health and well-being of older women around the world (Johnson, 2005; Public Health Agency of Canada, 2014; World Health Organization, 2007). In the United States (US), one in three adults over the age of 65 experiences an unintended fall annually (Lord, Sherrington, Menz, & Close, 2007). Compared to men of the same age, older women are more likely to fall and to suffer injuries that require hospitalization, including fractures and dislocations of the hip, knee, and wrist, among others (Lord, et al., 2007; Rossat et al., 2010; Stevens, Corso, Finkelstein, & Miller, 2006). The risk of falling increases with age-related changes to the cardiovascular, visual, and musculoskeletal systems (Ambrose, Paul, & Hausdorff, 2013). Regardless of the extent or type of any physical injuries, experiencing a fall may impact an older woman's independence and identity (Dollard, Barton, Newbury, & Turnbull, 2012; Stewart & McVittie, 2011; Yardley & Smith, 2002). Emotional responses to falls range from fear (Boyd & Stevens, 2009; Jørstad, Hauer, Becker, & Lamb, 2005; Roe et al., 2008) to identity crises (Dollard, et al., 2012; Stewart & McVittie, 2011). Among the elderly, restricted social and physical activities are commonly reported consequences of falls (Deshpande et al., 2008; Høst, Hendriksen, & Borup, 2011).

Findings from a study conducted in two primary care trusts in the northwest of England indicated older adults who reflected on their fall experiences were more likely to develop strategies to prevent future falls in contrast to harboring a continuing fear of falling among those who did not actively seek to understand how and why they fell (Roe, et al., 2008). Other commonly reported post-fall decisions and accommodations may

include receiving help in the home (Hashmi, Danish, Ahmad, & Hashmi, 2013; Remizov & Lungu, 2008) and using an assistive device (Fleming & Brayne, 2008; Hedberg-Kristensson, Ivanoff, & Iwarsson, 2007; Luz, Bush, & Shen, 2015).

Post-fall decisions may vary in accordance with women's residential settings and contexts. In the US, continuing care retirement communities (CCRCs) are residential settings where older adults live independently in a cottage or apartment, but have the on-site access to assisted living or skilled nursing setting if needed (Kohl, 2010). Following a fall, CCRC residents may be strongly encouraged by staff to wear and use a life alert system device and some may be transferred to a higher level of care (Krout, Moen, Holmes, Oggins, & Bowen, 2002). However, to date, few studies have focused on how older women from these settings make decisions after a fall. The purpose of this descriptive qualitative study (Sandelowski, 2000) was to explore the post-fall responses and decision-making processes among older women living in CCRCs.

Methods

Settings and Participant Recruitment

The research setting consisted of two retirement communities: *Bright Side* and *Happy Days* (pseudonyms used to protect the identity of the facilities and participants). *Bright Side* is a large religious-affiliated CCRC with approximately 400 residents, 185 of whom reside in independent living in cottages and apartments. *Happy Days* is a smaller religious-affiliated retirement community located in the same city, with 85 of the 100 residents living independently in cottages or apartments. Eligibility requirements were women aged 65 or older residing in a CCRC cottage or apartment, who had experienced a fall within the last six months which resulted in at least a minor injury (e.g., a wound,

bruise, or cut) and subsequent activity limitations for at least one day, English fluency, and no evidence of significant cognition or memory impairment.

A university Institutional Review Board (IRB) approved the research; in the process of requesting access to the sites we provided CCRC administrators with a copy of the IRB approval. To recruit participants we posted recruitment flyers and made formal presentations to inform residents of each CCRC of the opportunity to participate in the research. We trained a staff collaborator at *Bright Side* to assist in recruitment efforts. She identified 35 residents who had fallen in the last six months and screened their eligibility for the research. Subsequently she made individual contact with 22 women to explain the study, informally assess cognition and memory, and verify eligibility criteria before obtaining their approval to share their contact information with the research team. Of the 22 residents, 10 declined the invitation to participate in the research because they did not want to discuss their fall; a researcher subsequently contacted each woman to confirm her eligibility, formally invite her to participate, and schedule a time to conduct the in-person interview.

With the permission of the *Happy Days* administration, research staff directly contacted approximately 20 female residents while they waited to have lunch in the dining area, three of whom agreed to participate in an interview. Two additional participants from *Happy Days* were identified through snowball referrals by participants who told them about the study and provided them with our contact information. Prior to the interview participants provided written consent; at the conclusion each participant received a \$30 appreciation incentive.

Data Collection and Analysis

We conducted interviews with 17 CCRC residents, 12 at Bright Side and five at Happy Days, between December 2013 and June 2014. All participants provided written consent prior to initiating the audio-recorded interview. Interviews lasted between 30 minutes and 2.5 hours ($M = 60$). Each semi-structured interview focused primarily on an identified *indicator fall* the woman had experienced within the previous six months. When a woman had experienced more than one fall, the indicator fall was that which she identified as most significant, either in terms of severity (e.g., down and could not get up for hours) or consequences (e.g., broken bones). Probing questions prompted participants to reflect on the fall, describe her responses, and identify subsequent decisions and changes. Following the interview, each participant completed a 10-item paper and pencil demographic survey and a brief report of her indicator fall (i.e., date and location of fall, and type of injuries incurred in indicator fall).

The audio recordings were professionally transcribed according to format and content guidelines provided by the investigators; all identifying information was removed from the transcripts. For the descriptive qualitative analysis we adopted grounded theory coding approaches and techniques (Strauss & Corbin, 1998; Thomas & Harden, 2008). In the first phase of the analysis, three researchers independently coded a paper transcript of the same interview, employing line-by-line inductive open coding, then met and discussed the codes. Subsequently, the primary analyst open-coded the transcripts of the next three interviews, and created coding summaries and categories (e.g., *context of the fall, fall incident, meaning of the fall, post-fall actions*). To assist in managing the data, the transcribed interviews, field notes, and interpretive memos were uploaded into

separate folders in NVivo 10 (QSR International Pty Ltd, 2012) and the primary analysis continued the open coding process for the remaining transcripts. Throughout the concurrent data collection and analysis processes, the primary analysis continued to revise and refine the codes and categories, with ongoing guidance and corroboration provided by the qualitative methodologist on the research team. As the analysis progressed and new codes emerged, the analytic team, individually and collectively, began grouping codes into more specific categories (e.g., *ambulation, avoidance, assistance*) and eventually moved to axial coding which involved the review of all of the transcripts to identify variations and dimensions of the various categories (Strauss & Corbin, 1998). Interpretation of these categories and dimensions led to the construction of broader themes (e.g., *assessing personal physical and emotional needs, taking an out of mind approach, getting back to normal*). After comparing and contrasting the data from 17 interviews we concluded we had reached an acceptable level of data saturation and decided not to conduct further interviews (Morse, Barrett, Mayan, Olson, & Spiers, 2008; Patton, 2002). To analyze the demographic survey data, we entered participant responses into IBM SPSS® Statistics 22.0 (IBM Corp., 2013) and ran nonparametric frequencies and percentages.

Results

Participant Demographics

The 17 participants were well-educated white women between the ages of 82 and 98 years old (Table 1). They reported having experienced between one and three falls within the last six months; those who had experienced multiple falls chose one as the indicator fall for the purpose of the interview. The majority ($N = 14$) of these falls had

occurred inside the CCRC; three had occurred on a sidewalk outside the CCRC. The most frequent indoor locations were bedroom, hallway, and bathroom. Resulting hip, head, and arm injuries ranged in severity, with three out of 17 women requiring hospitalization for at least three days.

[Insert Table 1 here]

Themes

In reflecting on their recent falls, these older women described the experience as an *unexpected, sudden event* that had heightened awareness of their physical, emotional, spiritual, and social independence (i.e., “*Falling affects you physically and emotionally*”). For many, a major post-fall goal was to *get back to their normal routine*. Efforts to regain this sense of normalcy included *assessing personal physical and emotional needs in the context of the work of recovery; feeling burdened by the extra work; seeking and obtaining assistance and spiritual support; avoiding specific people, objects, and places; and planning ahead*. A few women reported having purposefully responded to the fall by taking an *out of mind* approach, which we defined as not taking specific actions but rather dismissing any broader meaning or significance associated with the fall. In the following sections we discuss these thematic findings in more detail.

The work of recovery: Assessing personal, physical, and emotional needs. A commonly reported immediate post-fall response was to focus on the physical ramifications of the fall. Post-fall assessment responses included reflecting on what had happened, the extent of the resulting injury and resulting physical needs, and figuring out possible solutions or further actions. Reported solutions or further actions included going to a physician for diagnosis and treatment, getting more rest, eating well, taking pain

medication, and using a neck brace or other mobilizing instrument to recover from their post-fall injuries. In several cases, the women did not deem the fall to be “*serious enough*” to warrant seeking a formal medical check-up.

These women’s emotional reactions to having fallen ranged from anger and embarrassment to “*feeling stupid*.” Some were aggravated with themselves because they “*can't even walk*” without falling. Others were in shock that they could not get up on their own after their fall and for the first time felt “*helpless*,” a feeling which further increased their new or already existing fear of falling. In some cases, the emotional toll of experiencing a fall may have played a greater role in the women's post-fall decision making than the fall injuries themselves. As these older women progressed through their post-fall recovery, they continuously reassessed their physical and emotional abilities, needs, and concerns.

The extra work and burden of dealing with their compromised physical status was another concern. Mrs. Jones, who cracked a rib and fractured her sternum as a result of her fall, noted that although “*it was never any trouble to hang up my clothes [now] it is an effort*.” The extra work involved in mobility and completing activities of daily living was both difficult and time consuming. Mrs. Smith commented that “*Anything that's far away I just can't do. I don't even try*.” This pattern of self-imposing activity limitations was reported by other residents.

“***Getting back to normal.***” A common response to having fallen was to engage in the work of returning to one’s normal routine. Four study participants actually used the phrase “*get back to normal*” when describing the goal of their post-fall activities. Despite the physical suffering that resulted from the fall and the resultant additional effort needed

to get around and complete tasks, these women took specific actions, such as engaging in rehabilitation and doing physical therapy to work on muscle strength and balance, in order to return to the pattern of activities they had prior to the fall.

Taking up previously well-established habits and health promoting practices, such as routine physical exercise, was a deliberate way some women worked to “*get back to normal.*” This sometimes required making minor modifications or temporary adjustments to their regular schedule (e.g., attending a fitness class without lifting the injured arm), but the goal was to return to this habitual behavior or activity pattern. Mrs. Foster noted, “*They advise to continue exercise, which I do three times a week, go to an exercise class. I was doing that before I fell and I continued it as soon as I could after that.*” Women sought to regain a sense of normality by returning to their regular routines, participating in social activities and meeting up with friends:

I was going to Sunday lunch in the dining hall with three other friends and that did not change. They just expected me to be wrapped around on this Rollator [i.e., a rolling walker], because I came back with a Rollator, and go meet them. And they expected me also to keep playing cards, which I did after I got the swelling down. So things went on like before. (Mrs. White)

Seeking and obtaining assistance and spiritual support. Regaining a regular routine often required the use of assistive devices or technology (e.g., wheelchair, walker, cane, hand reacher grabber, lift chair) and assistance from others for instrumental activities of daily living. While most women admitted their desire to stay independent as long as possible and not receive any assistance, some admitted they understood the need

to accept help. Mrs. Brown reflected, *“I think you know what you need and what you don't need. I was just more secure taking a shower, having somebody here with me when I got up in the morning.”* Some felt more stable and secure using a walker or holding on to people when ambulating.

Having been accustomed to living independently in a CCRC, these women acknowledged the personal costs and emotional work involved in graciously accepting assistance from others: *“Giving up your independence is really difficult, but I try to be as kind about it as I can because they're helping me.”* While family members did initiate some of these decisions, such as contracting temporary help, several participants reported having made the final decision to keep or reject this assistance based on their evolving physical and emotional needs and concerns. Mrs. Smith's response was representative: *“I had help around the clock. I finally got rid of them yesterday. I didn't really need them that much.”*

Faith was an important source of support for many women, but tended to be less visible and public. Without the need to publicly share the details of the fall and related injuries or concerns, women could privately solicit support from God through prayer. For women like Mrs. Campbell, faith was also a source of security and moral support: *“I have great faith in that the Lord knows my need and knows all about my situation, and I know that He'll take care of me.”*

Maintaining independence and privacy by avoiding people, objects, and places. Avoidance and adaptation were other approaches some women employed in negotiating whether or not to engage outside sources of assistance. Despite recommendations by both her family physician and physical therapist to use a walker for

ambulation, Mrs. Rice used the walker for a bookshelf, declaring, “*I may be 80 years old but I’m not ready to give up.*” These comments reflected her view that using and being seen with an ambulatory device signified loss of independence or self-will. Several others reported they purposefully avoided any type of assistance, even if they needed it, in an effort not to *appear* to be in need of relying on outside support.

This work of *getting back to normal* involved balancing these issues of privacy and independence with getting assistance from others or things. Another common response was the clearly stated preference and desire to avoid public disclosure and keep information related to the fall as private as possible. Participants described wanting to “*crawl in a hole*” while having experienced the commotion of a fall and the arrival of an ambulance. Strategies to avoid the public “*grapevine*” included pretending to be fine and telling “*little white lies*” to family members so they did not pay too much attention to the fall incident and related injuries. By avoiding attention to the fall incident and resultant physical limitations, women were also working to protect their self-image and worth.

Other avoidance strategies focused on preventing a future fall included restricting access to activities in certain environments judged to be too risky or unsafe. Mrs. West described a process of self-monitoring her own physical recovery progress and level of self-assurance: “*I still feel uncomfortable walking outside. I used to do that. I haven't reached a point where I'm comfortable because of my fall.*” These decisions appeared to be based on self-assessment of both one’s physical abilities and emotional state, such as fear and self-confidence.

Being proactive: Planning ahead, taking more time, and implementing safety measures. Being proactive often involved planning ahead and taking more time in order

to participate in different social activities organized at the CCRC. Planning strategies included “*going a little earlier than usual*” to get to the activities, taking extra time to get to a specific location, “*not being in a hurry anymore,*” and “*being more organized*” to bring what is needed because “*I can't just jump up and do it.*” Despite the extra effort required to plan ahead, it was a proactive response that indicated increased awareness of the environment and a strategy to reduce the risk of a repeat fall. Other examples of proactive strategies included implementing safety measures to help manage and prevent future falls. Some women had purchased night lights to be able to see where they walk at night or started wearing life alert systems to get immediate help from the CCRC staff in case of an emergency. Those who previously did not feel like they needed to wear their life alert pendant now carried it with them all the time: “*I'm never without it, 'cause with this I know I can get help.*” These instances suggest that having experienced a fall made these women more aware of the purpose and utility of such falls prevention and management tools, while also providing a sense of safety and security after their falls.

Putting the fall out of mind. In a few cases, women purposefully took an *out of mind* approach to manage this incident. They displayed a risk-free, worry-free, attitude and had deliberately decided to dismiss any meaning associated with their fall. These few women reported the fall was a single, independent, non-consequential event. Rather than stress about the incident and restrict her activities, Mrs. Black preferred to maintain her independence: “*If I worried about it, I never would go out of my apartment. I just forget it.*” Mrs. Turner's post-fall response also involved keeping her fall out of mind: “*I don't think about my fall. I really don't. I just don't dwell on it.*” For a few of the women, this intentional strategy served to help dissipate the worry that accompanied the fall and its

implications. However, in these cases, putting the issue out of mind meant not taking substantial actions to prevent future falls (i.e., attention to the walkway or use of a mobility device to enhance stability).

Discussion

The results from this exploratory research indicate a range of post-fall responses and decisions among older women living in CCRC settings. These included conducting personal physical and emotional self-assessments; engaging in the extra (and sometimes burdensome) work of getting back to normal; obtaining assistance from a variety of sources including faith; purposefully avoiding people, objects, and places; being proactive and planning ahead; and sometimes putting the fall *out of mind*. As evidenced in the analysis of these data, the responses of older women who have experienced a fall addressed physical, emotional, social, and spiritual concerns. These concerns were also a source of cognitive and emotional dissonance for the women as they tried to balance being in control and maintaining their privacy and independence while also being open and receptive to assistance that could help with their recovery. This work of worry, which was found to be present in most types of post-fall responses and decisions, was deeply embedded in women's decision making. Our findings also highlight the extensive emotional work involved in experiencing a fall and trying to get back to normal (Messias et al., 1997).

Several of the post-fall strategies reported in this research echo older adults' post-fall attitudes and actions previously reported. For example, past research has focused on getting back to normal, and more specifically, on engaging in physical activity and balance exercises after a fall (Mahler & Sarvimäki, 2010; Narita, Islam, Rogers,

Koizumi, & Takeshima, 2015). Accepting or rejecting assistive devices was also identified as important in older adults' post-fall experiences and associated with an increased sense of vulnerability and decline (Hedberg-Kristensson, et al., 2007; Luz, et al., 2015). Avoidance of certain locations or activities and self-imposed limitations and restrictions on activities were found to be common actions after a fall (Roberto & Reynolds, 2001; Zijlstra et al., 2007). Dismissing a fall as a random, unimportant event was also used in the past to protect a woman's self-identity (Hanson, Salmoni, & Doyle, 2009; Meadows, Mrkonjic, Petersen, & Lagendyk, 2004). Ultimately, the stress, fear, and humiliation reported after a fall (Boyd & Stevens, 2009; Roe, et al., 2008; Stewart & McVittie, 2011), which is often associated with a loss of independence, especially for those experiencing an important injury, were also mentioned in the literature (Mahler & Sarvimäki, 2010; Narita, et al., 2015).

The deliberate decision reported by a few participants to refuse any assistance and to avoid talking with others about the fall or their post-fall recovery is a finding of importance for family members, CCRC staff, or health care providers. Given the emotional work and meanings attributed to a fall, the reluctance of some older women to open up to others is not necessarily surprising (Messias, et al., 1997). However, this type of response has not been reported in the falls prevention and management literature. Health professionals and public health experts typically discuss different fall risk factors such as vision, medication management, balance, and gait (Smith et al., 2015). Our findings suggest the need for professionals and family members to be alert to the tendency to avoid help-seeking and develop post-fall intervention strategies that respect older women's desire for privacy.

Raising awareness of family members, CCRC staff, and providers about the variety of ways older women may respond to a fall event is also crucial so they consider how to effectively approach and provide post-fall recommendations and care. A contribution of this research is that it examines the post-fall response in CCRCs, this specific type of environment where residents have access to a continuum of care from independent living, assisted living, to skilled nursing (Kohl, 2010). Understanding the responses, decisions, and actions women make after a fall may have practical implications for the CCRCs who try to promote independent living among their residents.

It is important to raise older women's awareness of these different internal priorities as well as the various approaches and strategies they can use after a fall. Engaging older women around the globe to consider different ways of responding to a fall, but also guiding them towards more effective and healthy post-fall decisions (e.g., exercising and socializing instead of limiting their activities and being isolated) are needed to positively contribute to the women's post-fall decision-making processes and help them recover their health and quality of life.

We argue that these responses and decisions also have practical implications for health professionals and family members across cultural and social contexts. Dollard and colleagues (2014) recently found in Australia that most older women do not report their falls to their general practitioner (Dollard, et al., 2014). Garcia et al. (2015) found similar results in Brazil, where it was common for community dwelling older women to fail to self-report previous falls (Garcia, et al., 2015). Practical implications may include using specific communication techniques to discuss the fall with the woman and offer support without bringing public attention to her new disability. Healthcare providers can use tools

such as the Stopping Elderly Accidents, Deaths, and Injuries (STEADI) tool kit to start discussing and addressing the women's falls and fall risks (Centers for Disease Control and Prevention, 2015; Smith, et al., 2015). It is estimated that approximately 1.5 million falls could be prevented if only 5,000 healthcare providers followed the STEADI toolkit for five years to screen older adults for fall risk (Centers for Disease Control and Prevention, 2015). Nurse practitioners can use the post-fall index (Gray-Miceli, Ratcliffe, & Johnson, 2010; Gray-Miceli, Strumpf, Johnson, Draganescu, & Ratcliffe, 2006) to assess all aspects of an older woman's fall experience and improve fall prevention and reporting practices. Members of the women's social network can also focus on being present, listening, and potentially helping to address older women's strategies and outcomes of their post-fall decisions.

There also needs to be an important change in the social norms and attitudes of this generation towards falls and aging (Radina, Lynch, Stalp, & Manning, 2008). A fall and anything associated with it (e.g., being transported by ambulance to the emergency room, using a walker) should not always be perceived as an ultimate descent of one's life. Rather, among older women, a fall can and should be seen as an opportunity for positive change, through slight adjustments of one's activities or the acquisition of assistance through people or mobility devices that can support their active lives in society. Our findings suggest that for women to be able to regain their quality of life after a fall, perceptions and attitudes surrounding a fall need to change not only among older women, but also among family members, friends, staff, and health care providers. Although there is a continued need to focus on prevention, it is important to find a balance to prevent and, at the same time, not blame the victim. Only then will women truly be able to

recover more quickly from their falls, regain their health, and maintain their quality of life.

Limitations of this study include the composition of the sample and the scope of the data collected. Participants were white women, between the ages of 82 and 98 years old, living in two privately owned CCRCs. Although these findings may not represent the experiences of older women of other races, younger ages, and those living in other institutional and non-institutional environments (Creswell, 2009; Patton, 2002), this research provides a starting point for research on gender differences in post-fall decision-making among the elderly.

Future research is needed to explore how these post-fall decisions are made within women's social networks. How do members of women's social network (e.g., spouse, adult children, health care providers) play a role in the post-fall decision-making process? How active are they in the women's post-fall decision-making? Does the social network influence specific approaches and strategies that women make? We can reach a greater understanding of the post-fall decision-making process by exploring if and how these decisions are made alone or through women's social networks (Casado et al., 2009; Jenkins, 2003).

Other areas that merit investigation include how differing factors may affect specific decisions after a fall. Roberto (1992) started this work by examining the functional and psychosocial factors that influence the recovery of older women with hip fractures. Additional research is needed to examine how certain individual factors (e.g., self-rated health, health literacy, knowledge of care options) may play a role in CCRC

women's post-fall decision-making processes, and how these factors may be addressed to improve the women's recovery after a fall.

Researchers should also consider how these different post-fall responses may also apply to other health conditions. Several unexpected medical events such as strokes, heart attacks, and cancers can also bring about a sudden change in women's health and independence and lead to important decision making (Arslanian-Engoren, 2006; Hossen, Westhues, & Maiter, 2013; Roberto, Gigliotti, & Husser, 2005). Further research is needed to explore the types of decisions that are made after such medical crises to gain a better understanding of the overall post-event decision-making process and how best to respond with care and assistance.

More research is needed to further understanding of the possible relationships between risk factors (i.e., fall history, medical conditions, current medication) and post-fall decision-making processes. In this descriptive qualitative research we explored older women's responses and decisions after a fall. The findings provided insight into the balancing work that women engaged in to protect their privacy and independence, access needed assistance, and maintain their physical well-being and quality of life. In developing falls prevention and management programs, services, and clinical recommendations, clinicians, social service providers, and policy makers need to consider older women's priorities and approaches to maintaining and regaining their health after a fall.

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TABLE 4.1: Participant Demographics, $N = 17$

Sample Characteristics	Mean (SD) or Frequency (%)	Range
Age	88.9 (3.9)	82-98
Race/Ethnicity		
White	17 (100%)	
African American	0 (0%)	
Marital status		
Married	3 (17.6%)	
Widowed	14 (82.4%)	
Education		
Less than high school	1 (5.9%)	
High school degree or GED	2 (11.8%)	
Some college	6 (35.3%)	
Bachelor's degree	7 (41.2%)	
Advanced/Graduate degree	1 (5.9%)	
Living situation		
Living with spouse/partner	3 (17.6%)	
Living by herself	14 (82.4%)	
Years living in the CCRC	6.1 (4.3)	1-16
Number of falls in the last six months ^a	1.4 (0.7)	1-3

^a The number of falls changes significantly with age ($t_{(16)} = 8.172, p = 0.000$).

TABLE 4.1 (continued): Participant Demographics, $N = 17$

Sample Characteristics	Mean (<i>SD</i>) or Frequency (%)	Range
Location of fall		
Outside	3 (17.6%)	
Sidewalk	3 (100%)	
Inside	14 (82.4%)	
Bathroom	2 (14.3%)	
Bedroom	5 (35.7%)	
Living room	1 (7.1%)	
Hallway	5 (35.7%)	
Lobby	1 (7.1%)	
Fall injuries ($N = 35$ self-identified injuries subsequent to 17 falls) ^b		
Torso	13 (76.5%)	
Head and neck	12 (70.6%)	
Upper extremities	6 (35.3%)	
Lower extremities	4 (23.5%)	

^b The percentages may not add up to 100% as the older women may have suffered more than one injury during their fall.

4.2 Manuscript 2

Involvement of Family Members and Professionals in Older Women's Post-Fall Decision Making²

² Bergeron, CD, Messias, DKH, Friedman, DB, Spencer, SM, & Miller, SC. Submitted to *Ageing and Society*

Abstract

This study explores the involvement of family members and professionals in older women's decision making after a fall. We conducted semi-structured qualitative interviews with 17 older women who had fallen within the past six months and 11 secondary informants, individuals the women identified as being involved in their post-fall decision-making processes, in the southeast United States. We employed open and axial coding in analyzing and interpreting the interview data. After having experienced a fall, these older women's openness to others' opinions and advice, their assessment of the types and credibility of the potential information sources, and the relationship patterns they established with these sources influenced the ways in which they accessed, accepted, or rejected information from family members and professionals. Information sources with whom women had previously established open communication patterns reported being more engaged in post-fall decision-making. The desire to maintain their personal independence also figured into these older women's openness to receiving information or advice from others. Perceptions of professionals as more credible and knowledgeable contributed in part to some preferences for professionals over family members as sources of information and advice. Increased awareness of the involvement of others in post-fall decision making could help enhance communication about post-fall concerns with any older woman who experiences a fall. Developing and implementing practical strategies to help family members and professionals from a variety of backgrounds, including geriatrics, nursing, social work, physical therapy, and occupational therapy, among others, to initiate conversations about falls and their consequences could lead to more open decision making among older women, both before and after a fall.

Key words: Falls; Older Women; Information Sources; Decisions; Qualitative Research

Background

Older adults tend to have confidence in their ability to make their own decisions; compared to younger persons, they tend to seek less information in the process (Mather 2006; Zwahr 1999). Some research suggests that older adults' judgmental wisdom contributes to their ability to discern the difference between regular and irregular choices, which may contribute to making better decisions (Tentori *et al.* 2001: B95). Older adults' motivation or willingness to engage with a decision also impacts their ability to make good decisions (Strough, Bruine de Bruin and Peters 2015). However, their decision-making performance appears to decline when making complex decisions with multiple options (Del Missier *et al.* 2015; Frey, Mata and Hertwig 2015). Furthermore, living with a chronic illness (i.e., cancer, Parkinson's disease, AIDS) or being hospitalized for an acute illness (e.g., a stroke) can impair older adults' decision-making abilities (Dekkers 2001; Fitten and Waite 1990; Moye and Marson 2007; Wang and Nolan 2015). Although experiencing a fall may or may not result in diminished decision making similar to these other conditions, little is known in general about older adults' post-fall decision making. Post-fall decision making refers to assessments, choices, and actions women make after experiencing a fall, particularly decisions related to personal health and independence, recovery from the fall injuries, and/or prevention of future falls. Examples of post-fall decisions would be to remove rugs, use a walker, avoid specific locations or activities, and use assistive devices. For older women who are accustomed to making their own decisions and who also are more likely to fall and be hospitalized due to their fall injuries, experiencing a fall may result in additional emotional, social, and functional work (Lord 2007; Schiller *et al.* 2007; Werner 2011). Because individuals with

diminished autonomy tend to seek help from others in the decision-making process (Schmid *et al.* 2010; Silveira, Kim and Langa 2010), given older women's increased sense of vulnerability after a fall, they may be more open to shared decision making, soliciting and sharing information, and/or accepting decisional assistance (Brown *et al.* 2002; Strough, Cheng and Swenson 2002).

Shared and collaborative decision making refers to the process whereby the patient and the health care professional share information, discuss different health care options and the pros and cons of each, and come to consensus on an action that will produce the most satisfying outcomes (Makoul and Clayman 2006; Murray, Charles and Gafni 2006; Trede and Higgs 2008). Shared decision making is not limited to patients and health care providers. Older adults' shared, collective decision making may involve family members and a variety of professional or other support people (Friedman *et al.* 2012; Miller *et al.* 2014; Shawler, Rowles and High 2001; Wolff *et al.* 2009). However, there is limited research on the actual processes and content of older women's shared decision making after a fall. The purpose of this descriptive qualitative research (Sandelowski 2000) was to explore older women's post-fall health and recovery decisions. The specific aims of this study were to (1) describe the involvement of family members and professionals in this post-fall decision making, and (2) examine how older women accessed, incorporated, or rejected information in making their post-fall decisions.

Design and methods

Participants

We recruited older women living on their own independently in two continuing care retirement communities (CCRCs) in the southeast United States to participate in the research. We obtained approval from a university Institutional Review Board (IRB) and provided a copy of the IRB approval to administrators at both CCRC sites prior to initiating recruitment and data collection. Inclusion criteria were English-speaking women, 65 years of age or older, who presented no evidence of cognition and memory issues as assessed informally by CCRC staff and had experienced a fall within the previous six months that resulted in at least a minor injury, such as a bruise, a cut, or pain that limited their activities for at least one day. We recruited participants through flyers, formal presentations, and by word-of-mouth. A staff collaborator also recruited participants at one CCRC. She identified 22 residents who met the eligibility criteria, individually approached them, explained the research, and if they indicated a willingness to participate, provided us with their name and contact information. The study sample consisted of 17 older women, referred to as *primary informants*, with whom we conducted an on-site interview focused on their post-fall decision making. At the completion of the interview, the interviewer asked each woman to identify up to three individuals (i.e., *secondary informants*) who had been involved in her post-fall decision making. Each participant then ranked these individuals according to their level of post-fall decision-making involvement and provided contact information. Among the primary informants, two women reported they did not involve any interpersonal sources of information after their falls and four participants declined to provide contact information

for the individuals they identified as information sources. The total sample included 17 women who had experienced a fall (i.e., primary informants) and 11 individuals these participants identified as information sources (i.e., secondary informants). At the conclusion of each interview, participants received US \$30 (cash or an equivalent value gift card) in recognition for their time and contributions to the research.

Data collection

We developed separate semi-structured interview guides for the primary and secondary informants which we pilot-tested with a community-dwelling older woman who had recently experienced a fall and her spouse, who had been involved in helping her make decisions after her fall. Following the pilot interviews we made minor adjustments to the format and wording of the interview guides. The primary informant interviews focused on the older women's recent fall experiences, their post-fall decision making, the type of information or advice they sought or received from others related to post-fall decision making, their relationship to the individuals they identified as information sources, and the perceived credibility and trustworthiness of these information sources. The interviews with the secondary informants focused on their relationship with the primary informant, their level of involvement in her post-fall decision making, and the type of information or advice they had offered regarding post-fall decisions or actions.

We conducted all of the interviews between December 2013 and June 2014. Primary informant interviews lasted between 30 minutes and 2.5 hours ($M = 60$ minutes). The secondary informant interviews lasted between 20 minutes and 1.5 hours ($M = 40$ minutes). The interviews were audio recorded using both a digital recorder and an audio

recorder on a cellular telephone. The audio recordings were transcribed by professionals according to guidelines we provided them on format and content. We removed all identifying information from the transcripts and used pseudonyms to protect the participants' identities.

At the conclusion of the primary informant interviews, each participant completed a ten-item paper and pencil survey with demographic questions (e.g., year of birth, race, marital status, education) and questions on her fall (e.g., location of most important fall, injuries experienced). Similarly, each secondary informant completed a nine-item demographic survey providing information on his or her age, race, marital status, education, income, relationship to and frequency of communication with the primary informant, and perceived importance and involvement in her post-fall decision making.

Data analysis

Employing grounded theory coding techniques (Strauss and Corbin 1998; Thomas and Harden 2008), the focus of the analysis was to explore the post-fall decision-making processes these older women engaged in and the ways in which other individuals participated in these decisions. We began the analysis by involving multiple investigators in an iterative line-by-line inductive open coding process of two individual interviews. In subsequent coding, the primary analyst used NVivo 10 (QSR International Pty Ltd 2012) as a format for recording and sorting codes. We subsequently created summaries of the codes and categories that were emerging (e.g., direct and indirect decisions, type of advice provided, factors such as knowledge and previous experience affecting decision making).

We used a constant comparison method to examine codes within each interview and across the set of older women's interviews; by dyad (i.e., each older woman and her information source) and across the entire sample (Silverman 2013). The process involved identifying similarities and differences, grouping similar codes, making comparisons, and identifying broader categories (e.g., woman-directed decision making, caregiver-directed decision making, collaborative decision making). Within each category we then delineated specific attributes and dimensions of each one (e.g., independence, trust, and communication). We continued the axial coding process, reviewing all transcripts to identify variations within and across each category (Strauss and Corbin 1998) and eventually identifying three broad themes. When multiple revisions did not yield any distinctly different major categories, we made a consensual determination that we had reached data saturation for this specific analysis (Morse *et al.* 2008; Patton 2002). We used IBM SPSS® Statistics 22.0 (IBM Corp. 2013) to compute nonparametric frequencies and percentages for participant demographic data.

Results

We conducted a total of 28 interviews with 17 primary informants (See Table 4.2) and 11 secondary informants (See Table 4.3). The primary informants were all white women between the ages of 82 and 98 years old who had experienced at least one fall within the past six months. The secondary informants included seven family members (two husbands, three daughters, and two sons) and four professionals (one CCRC staff, one physician, one periodontist, and one physical therapy assistant). They ranged in age from 31 to 93 years old and the majority (82%) reported maintaining communication with the older woman every day or a few times per week. The women's reported falls

occurred in different locations around the CCRCs and resulted in injuries to the head and neck, torso, and upper and lower extremities (See Table 4.4).

In reflecting on their recent fall experience, these older women reported they had made decisions and taken actions related to their personal health and independence, involving family members and professionals to varying degrees in these decisions. The focus of this analysis is the involvement of these other individuals in older women's post-fall decision making. In the following sections we describe three salient findings related to older women's involvement of others in their post-fall decision making: 1) *the degree of these older women's openness to reliance on others*; 2) *their assessment of types and credibility of information sources*; and 3) *the relationship patterns evidenced in participants' recollections of post-fall shared decision making*.

Openness to reliance on others

In examining how these older women made decisions after a recent fall, we found considerable variation in their reported degree of openness to both soliciting and receiving information and advice from others. Not surprisingly, we found an individual woman's level of personal independence prior to experiencing a fall factored into the ways and degree to which she made and involved others in her post-fall decisions. Women who appeared to be quite independent prior to experiencing a fall (i.e., they walked by themselves, made their own beds, had their own routine, and attended social events without requiring direct assistance from others) tended not to rely on others in making post-fall decisions. Some decisions (e.g., deciding to "*be more careful*") were not particularly difficult to make and did not require others' input. However, some participants reportedly maintained a deliberate stance of independence related to their

post-fall decision making, even when involving others in the process would have been helpful. For example, Mrs. Brown reported, *“I made my own decisions. My children didn't influence me in any way.”* Not only were some women less open to requesting or receiving decisional assistance, they also tended to restrict divulging information about the fall as much as possible. Mrs. Turner's daughter noted, *“There were quite a few falls that I didn't even know about or didn't know the extent of them.”*

In contrast, women who involved others in making post-fall decisions reported having actively solicited outside advice and engaged others in making decisions about how to proceed. For example, Mr. Foster described how his wife explicitly asked him for advice after her fall, recalling their conversation that had gone like this:

Mrs. Foster: *“So, what do you think I should do here?”*

Mr. Foster: *“Well, you can do so-and-so.”*

Mrs. Foster: *“Okay. Well, I'll do that.”*

Women who reported being open to others' participation in their post-fall decision making tended to recognize their need for advice and valued input and support from others. Mrs. Jones related how she obediently followed her doctors' orders: *“I don't do anything unless my doctor tells me. She tells me what medicine to take and when I can exercise.”* Others, like Mrs. Smith, readily admitted to trusting and following their adult children's advice: *“My daughter tells me what to do. [Laughing] I mean I always consult her. She's very smart and good, but I usually do what she says.”* Acknowledging their own diminished physical capacity and/or cognitive independence made some women more open to decisional support.

Several participants reported actively soliciting others' opinions and advice, but they clearly maintained their personal decision-making power. This pattern could be frustrating for adult children, who felt their input had little impact on their mother's decisions. As Mrs. Campbell's son Ron reflected, "*I wish I could be more effective. You know, she's pretty stubborn, and she listens and is polite and tells me she appreciates my concerns, but she does what she wants.*" Even within this relatively small sample, there was a wide range of reported parent/adult child decision-making patterns. Several family members reported they had engaged in some discussion of options with the parent or spouse, but ultimately made the final decision *for*, rather than *with* her.

Assessment of information sources: Types and credibility

After experiencing a fall, these older women reported assessing both the information source (i.e., family member or professional) and their credibility. They tended to perceive professionals as credible, trustworthy, and knowledgeable sources of information. Both the older women and professionals recalled their interactions and reported that the women had asked questions about their health, were willing to discuss different options, and were attentive when the professionals made the effort to explain different processes. Mrs. Anderson, a CCRC employee, recalled the focus and content of her communication with Mrs. Moore:

Communication about the therapy program and sort of explaining to her the steps it takes to get there, and communication with the hospital, the doctor has to order it, all those other sorts of things. So communicating the programmatic and then answering any questions that she asked.

Perhaps because of their more formal relationship with the clients, the secondary sources who were CCRC staff or health care professionals reported communications in which they actively listened and made suggestions: *“I’ve told her to do what she feels like doing. If it hurts, don’t do it and if she feels like doing more, do a little more, but to rest when she needs to rest.”* Participants’ accounts of post-fall communications with professionals portrayed interactions that were direct and clear in which the interactants adhered to more prescribed, formal roles and communication patterns, such as asking for and receiving specific information or advice. In reflecting on her communication with Mrs. Jones’s, her physician noted, *“I think her feeling was like, I’m [the physician] gonna do the best thing for her and that if I can help, I am gonna help.”*

In some cases, women admitted not having been completely open and honest with others. Possible underlying reasons for the lack of disclosure range from personal pride to fear of being moved to another level of care (i.e., assisted living). However, in most cases, women trusted the professionals with whom they regularly interacted and relied on them for aspects of their post-fall decision making. In contrast, these older women perceived family members as available, helpful, and trustworthy sources of information, but not necessarily the most credible sources of information in their post-fall decision making. One advantage associated with professionals’ credibility was their level of formal education and knowledge: *“They’re professionals; they knew what they were doing.”* When family members had obtained formal education in a relevant field, the women perceived them as more credible: *“My daughter is getting a degree in counseling and so she’s pretty knowledgeable.”* Women who perceived a lack of credibility among

information sources reported difficult interactions and communications related to post-fall decision making.

Family relationship patterns and post-fall shared decision making

Compared to their reported interactions and communications with professionals, there was a much wider range of communication patterns and interactions between these older women and their family members. Among the seven family members, three who reported having very open and honest relationships with the older woman gave examples of the strategies they used to bring up sensitive issues (e.g., “*Mom, what are these bruises on your arm?*”). They reported discussions of key concerns that involved eliciting the older woman’s preferences, and together identifying various pros, cons, and potential costs associated with specific decision options. In recalling his communication with his mother about her fall, Mr. Wilson noted, “*We’ve been very open about it. If she has a problem, she brings it up to us. Or if we see something we don’t like or have concerns with, we bring it up and talk to her about it.*” When more open and collaborative family relationships existed, the older woman reported being receptive to the discussions and taking a more active decision-making role.

Among the secondary informants who were family members, four reported some type of disconnect had occurred during their post-fall decision-making process. This was particularly evident in relationships with adult daughters and sons, where the potential shift in the existing parent-child relationship seemed to cause several communication barriers. There were cases in which the older women intentionally kept information about their falls private by hiding information from their adult children or pretending to be okay. Mr. Campbell noted that his mother deliberately changed the topic when he

approached the topic of her fall: *“I think it’s primarily from her not wanting to talk about that.”* Several women reported having intentionally refrained from asking for help, unless it was extremely necessary. Mrs. Miller aptly noted, *“I’m not a person that asks.”* There was a clear focus on maintaining their own independence in order to not be a burden on their adult children, who had family responsibilities of their own. Yet several adult children reported they deliberately reminded their mother about their availability and willingness to help: *“Momma, anytime you want me, just call me. I will be there.”*

In contrast, two participants’ daughters noted they purposefully avoided bringing up the topic of their mother’s fall, so as not to *“hurt her feelings.”* Perhaps not wanting to be perceived as confrontational or intruding, some adult children waited for their mothers to bring up the subject of the fall or to specifically ask for help. Mrs. Park’s daughter noted her mother *“never brought it [the fall] up again, so I just kind of listen and monitor how things are... but she hasn’t brought it up anymore.”* Others, however, who wanted to make a suggestion or bring up the topic of the fall would do so by carefully weighing their words, beating around the bush, or using humor to avoid overstepping their mother's independence. Some adult children reported purposefully hiding information from their mothers because they assumed the older women would disagree with certain decisions they had made. Mrs. Campbell’s son reported that despite the fact that his mother had *“led us to believe”* that she had an appointment to see her doctor, he found out she actually had not made an appointment, so he intervened to make her one. Another example of this type of *behind the scene follow-up* was that every time family members came to visit Mrs. Campbell, they brought a replacement night light for the bathroom,

explaining: *“We put a night light in her bathroom after her fall. She'd take them out and not put them back, so we put 'em back in.”*

The involvement of family members in women's post-fall decision making tended to reflect well-established relationship and communication patterns. Some families were accustomed to open and trusting communication, whereas other elderly parents and their adult children were dealing with ingrained negative patterns that were difficult to change:

I'm not going to tell her what to do. It's funny, cause you want to tell them, as they did when you were younger, “I think I need to make this decision for you,” but I just can't do that. (Mrs. Turner's daughter)

Rather than taking an active role in the older adult's woman's post-fall decision making, several family members reported offering, and providing emotional support and encouragement: *“You're gonna be all right, Momma. You're gonna be okay. Don't worry.”* Other forms of instrumental assistance included driving the woman to appointments and encouraging compliance with recommended treatments (i.e., *“My husband encouraged me to do it [physical therapy] and then encouraged me as I went along with the sessions”*).

There were wide variations in the types and patterns of involvement in post-fall decision making, most of which were a function of the older woman's relationship with her various information sources. For example, relationships with CCRC staff depended in part on the length of time the woman had been a resident or the staff had been employed. Although some women reported long-standing relationships with the same physician, these professional patient-provider relationships differed from the long-standing, closer, and more in-depth relationships with close family members. In summary, the

involvement of family and professionals in older women's post-fall decision making varied widely. The woman's openness to reliance on others, the type and perceived credibility of the source, and pre-existing relationship and communication patterns all contributed to their post-fall decision-making processes.

Discussion

In this research we explored the involvement of family members and professionals in older women's post-fall decision making. Our analysis and interpretations of the interview data revealed that the degree of openness to reliance on others, the women's assessment of the types and credibility of the information sources, and the relationship patterns established with their source influenced whether older women accessed, incorporated, or rejected information from their secondary informants after a fall. Our interpretations of the data suggest these older women's openness to reliance on others depended on their own self-perceptions of independence, self-sufficiency, and sense of identification with their decision-making activities (Lloyd *et al* 2014). Among the primary informants, those who considered themselves to be self-reliant prior to having fallen continued to prefer to make their own personal choices and decisions after the fall (Bell and Menec 2015; Moorman 2011). Those women who recognized a significant change in their physical abilities after having fallen were more open to relying on others for decision-making assistance.

In prior studies, other researchers have described the need for older women to turn to their social support networks for assistance in health care decision making (Brown *et al.* 2002). There is evidence that physicians remain older adults' most trusted source of information (Burns *et al.* 2013; Chaudhuri *et al.* 2013; Hesse *et al.* 2005) and are often

assigned the decision-making authority (Arora and McHorney 2000; Levinson *et al.* 2005). Our findings also suggest that health professionals' training and level of education contribute to their perceived credibility (Burns *et al.* 2013; Donohue *et al.* 2009).

These in-depth interview data indicated a tendency among these older women to only confide in or request information from trusted individuals. Older adults may feel they risk losing independence and pride by reaching out to and relying on others for decisional support (Adelman, Greene and Ory 2000; Castelfranchi, Falcone and Marzo 2006; Norman and Sycara 2011). To protect their self-esteem, older women living in group residential settings may take actions to avoiding public dissemination of the fact that they have fallen. Geriatricians, nurses, social workers, physical therapists, occupational therapists, and other geriatric health care professionals should be aware of the different post-fall concerns older women have and proactively initiate conversations about falls, as they do for other health conditions, because many older adults may purposefully avoid disclosing a fall with a primary care provider (Bowman *et al.* 2010; Lee *et al.* 2013).

Adult children's relationships with their elderly parents can be challenging, in part because of the ambivalence accompanying shifting responsibilities between the parent and the adult child (Spitze and Gallant 2004). Among this sample of older women who had recently experienced a fall, participants' clear desire to maintain their personal independence was countered by varying degrees of openness to receiving decisional support from others. The secondary informants, and especially the adult children, also discussed their feelings of ambivalence about wanting to tell their mothers what to do without imposing their decisions or limiting her degree of independence. These findings

are consistent with Pecchioni's (2001) research on decision making in family caregiving and the potential for denial associated with health issues in old age. We found some adult children reported a variety of strategies (e.g., using humor) in order to avoid having direct and explicit discussions with their mothers about her fall, while still fulfilling their filial obligation of taking care of an ageing parent (Cooney and Dykstra 2011; Daatland, Herlofson and Lima 2011). Communication strategies may have also varied by gender of the adult child, although our small sample size did not allow us to assess these differences (Horton and Arber 2004). Family members, including spouses and adult children, may not know how to approach or feel comfortable in discussing what they can do, either alone or together, to manage the health and social consequences of the fall and prevent repeat falls (Edwards and Chapman 2004b). Among this convenience sample of elderly CCRC residents, we found women reported being more comfortable or open to communicate with professionals with whom they had shorter-term, less intimate relationships than with family members. However, because they also identified family members as the main sources of information after a fall, there is clearly a need for formal or informal training to improve intra-family communication regarding post-fall decision making among elderly women.

Implications of these findings include the recommendation to develop communication programs targeting family members and professionals. The dual purposes of such programs would be to raise awareness of the range of communication patterns that may occur after a fall and to provide family members, staff, and health and social service providers with options, strategies, and skills to help them establish more open and honest relationships with the older women, with the aim of creating more productive

shared decision making (Fine and Glendinning 2005; Guimond *et al.* 2003; Ryan *et al.* 1995; Weitzman and Weitzman 2003). Suggestions and advice for family members and professionals on how to better communicate with older adults do exist (Edwards and Chapman 2004a; Hardin 2012; Hingle and Robinson 2009; Robinson, White and Houchins 2006; Stein *et al.* 2014). However, there are few practical interventions designed with the goal of raising awareness of these communication patterns (Fried *et al.* 2005; Gutheil and Heyman 2005).

Decision making is often a collective process conducted by a constellation of individuals (Shawler *et al.* 2001). In this research, although we asked each primary informant to identify several key individuals who helped her make post-fall decisions, we only subsequently interviewed one secondary informant for each participant. Several primary informants also refused to provide contact information for potential secondary informants. There is clearly a need for further research on older women's post-fall decision making that includes a wider constellation of family and professional participants (Sheehan and Petrovic 2008). Other areas for further investigation include the experience of older men after a fall and the involvement of family members and professionals in the decision-making process. Given the demographic limitations of our sample of older white women residing in CCRCs, research with more diverse older populations (i.e., older men, other racial/ethnic identities, other residential configurations and settings) is warranted.

This research contributes to the literature on the involvement of professionals and family members in older women's decision making after a fall. In addition to suggestions for future research, we offer practical guidelines for professionals, family members, and

older women to improve their communication and relationships in order to be actively engaged in the post-fall decision-making process. The involvement and decisional support of family members and professionals may be instrumental in ensuring that an older woman who experiences a fall receives prompt post-fall treatment in order to ensure adequate recovery and prevent future falls.

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TABLE 4.2: Characteristics of primary informants (N = 17)

Sample characteristics	Mean (SD) or frequency (%)	Range
Age	88.9 (3.9)	82-98
Education		
Less than high school	1 (5.9%)	
High school degree or GED	2 (11.8%)	
Some college	6 (35.3%)	
Bachelor's degree	7 (41.2%)	
Advanced/Graduate degree	1 (5.9%)	
Current marital status		
Married	3 (17.6%)	
Widowed	14 (82.4%)	
Living situation		
Living with spouse/partner	3 (17.6%)	
Living alone	14 (82.4%)	
Years of residence at the CCRC	6.1 (4.3)	1-16
Number of reported falls in the last six months ^a	1.4 (0.7)	1-3

^a The number of falls increases significantly with age ($t_{(16)} = 8.172, p = 0.000$).

TABLE 4.3: Characteristics of secondary informants (N = 11)

Sample characteristics	Mean (SD) or frequency (%)	Range
Relation to primary informant		
Daughter	3 (27.3%)	
Husband	2 (18.2%)	
Son	2 (18.2%)	
Physician	1 (9.1%)	
Periodontist	1 (9.1%)	
Physical therapist assistant	1 (9.1%)	
CCRC staff	1 (9.1%)	
Gender		
Female	6 (54.5%)	
Male	5 (45.5%)	
Age	60.4 (17.4)	31-93
Race/Ethnicity		
White	9 (81.8%)	
African American	2 (18.2%)	
Education		
High school degree or GED	1 (9.1%)	
Some college	3 (27.3%)	
Bachelor's degree	2 (18.2%)	
Advanced/Graduate degree	5 (45.5%)	

TABLE 4.3 (continued): Characteristics of secondary informants (N = 11)

Sample characteristics	Mean (SD) or frequency (%)	Range
Income		
\$20,000-\$39,999	1 (9.1%)	
\$40,000-\$59,999	1 (9.1%)	
\$60,000-\$79,999	0 (0.0%)	
\$80,000-\$99,999	1 (9.1%)	
More than \$100,000	8 (72.7%)	
Frequency of communication with primary informant		
Multiple times a day	3 (27.3%)	
Once a day	1 (9.1%)	
A few times a week	5 (45.5%)	
A few times a year	2 (18.2%)	
Self-assessment of post-fall decision making involvement		
Somewhat involved	2 (18.2%)	
Involved	1 (9.1%)	
Very involved	8 (72.7%)	
Perceived importance of involvement in post-fall decision-making		
Somewhat important	4 (36.4%)	
Important	2 (18.2%)	
Very important	5 (45.5%)	

TABLE 4.4: Characteristics of the older women's reported falls within previous six months (N = 17)

Location of fall and resultant injuries	Frequency (%)
Location	
Bedroom	5 (29.4%)
Hallway	5 (29.4%)
Sidewalk	3 (17.6%)
Bathroom	2 (11.8%)
Living room	1 (5.9%)
Lobby	1 (5.9%)
Resultant injuries (N=35 self-identified injuries subsequent to 17 falls)	
Torso	13 (76.5%)
Head and neck	12 (70.6%)
Upper extremities	6 (35.3%)
Lower extremities	4 (23.5%)

4.3 Manuscript 3

An Exploratory Survey of Older Women's Post-Fall Decisions³

³ Bergeron, CD, Friedman, DB, Spencer, SM, Miller, SC, Messias, DKH, & McKeever, R. To be submitted to *Quality of Life Research*

Abstract

Purpose: This research examined factors that may influence post-fall decision making among independent, elderly women. The broader aim was to gain insight into how older women make decisions in managing the consequences of a fall. **Methods:** We developed a 67-item exploratory survey to assess participants' health, falls, post-fall changes, and decision-making processes. A purposeful, convenience sample of 130 independent women aged 65+ who had experienced a fall within the last 12 months responded to the survey. In analyzing the responses, we categorized women's post-fall decisions into three major categories – medical, corrective, and social – and then examined the relationship of these categories to their reported decisional conflict. We also examined the associations between decisional conflict and number of post-fall changes, self-rated health, frequency of falls, severity of falls, health literacy, familiarity with care options, openness to care options, and demographics. **Results:** The results of the multiple regression analysis indicated that category of post-fall decision was significantly associated with decisional conflict. Older women reported experiencing greater decisional conflict when making medical decisions compared to social decisions ($p = .01$) and corrective decisions ($p = .05$). Significant predictors of decisional conflict were familiarity with assisted living ($p = .04$) and health literacy ($p = .01$). **Conclusions:** For older women aiming to regain or maintain their quality of life after a fall, making medical decisions may be more challenging than other types of decisions and low health literacy may contribute to decisional conflict. Educational interventions for older women, their family members, health professionals, and personal care providers should address knowledge deficits and provide resources to enhance collaborative efforts to lower

women's post-fall decisional conflict and increase their satisfaction and implementation of the decisions they make after experiencing a fall.

Key words: falls; older women, survey, decision making, decisional conflict, health literacy

Introduction

For decades, researchers have examined risk factors for falls among older adults [1-3] and assessed fall prevention interventions and strategies [4-9]. In the United States (US), current data indicate one in three older adults experience a fall annually [10]. Older women fall more frequently than older men and are hospitalized more often for fall-related injuries [11-14]. Accidental falls resulting in injuries such as a hip or wrist fractures can severely impact health and quality of life [15-21].

Older adults may respond to a fall event and related injuries in a variety of ways [22]. Some may follow a rehabilitation plan after a fracture and work toward regaining independence in their activities of daily living [23], whereas others may engage in exercise programs to improve their physical strength and mobility [24-26]. However, when a fall is accompanied by significant psychological distress and fear, self-restriction on participation in social activities may ensue [27-29]. Given the myriad of physical, psychological, and social health implications, the frequency and consequences of older women's post-fall experiences merit attention of researchers and health service providers [30; 31]

The personal meanings associated with falls and disabilities constitute a primary focus within the existing body of research on post-fall experiences in older adulthood [32-38]. A less-studied phenomenon is post-fall decision making among older adults.

Post-fall decision making is a complex process involving choices about how to respond to and address the causes and consequences of the fall (including treatment of injuries), and whether or not to take specific actions to prevent recurrent falls. For some older adults, the decision may be not to make any deliberate changes in one's routine, habits, or gait [39]. There is some evidence that suggests older women tend to make at least a few post-fall changes, including environmental and/or behavioral changes such as being more careful or avoiding places where they might fall, although this has never been directly examined [6; 40; 41].

As with any decisional process, post-fall choices may involve some degree of uncertainty. This uncertainty and difficulty choosing a course of action is referred to as decisional conflict [42-44]. Manifestations of decisional conflict include verbalizing uncertainty about the choices and concerns about the undesired outcomes, shifting between different options, postponing the decision, questioning personal values, being preoccupied with the decision, and showing signs of distress [45]. After a fall, an older woman who experiences less decisional conflict regarding her personal health and independence is expected to be more satisfied with her decision, which should increase the chances of her following through on her decision and actions [46].

Several elements that contribute to increasing decisional conflict include inadequate knowledge about the situation or options, unclear values or norms, unwanted pressure by others involved in the decision-making process, and inadequate decisional support and/or resources [44]. Considering the nature of these elements (e.g., knowledge, understanding), we also expected certain other factors to be associated with decisional conflict such as one's familiarity and openness to care options, one's self-rated health, and

one's health literacy. For example, we hypothesized that individuals with less knowledge or familiarity with a care option such as adult day care would experience greater decisional conflict when considering this care option after a fall. As self-rated health, and specifically, low self-rated health, has been found to predict fear of falling and subsequent falls, we hypothesized self-rated health to be associated with post-fall decisional conflict as well [41]. Health literacy, the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions, has previously been associated with decisional conflict [47; 48; 49]. Individuals with lower health literacy experience greater decisional conflict because of this limited knowledge and/or ability to use health information for decision making. However, to our knowledge, the association between health literacy and decisional conflict in post-fall decision making has not been examined.

Research Aims and Methods

The three major aims of this research were to: 1) identify the types of decisions older women make about their health, independence, and quality of life after experiencing a fall; 2) examine possible relationships between post-fall decisions and decisional conflict and 3) investigate possible relationships between decisional conflict and specific individual factors including number of post-fall changes, self-rated health, frequency of falls, severity of falls, health literacy, familiarity with care options, openness to care options, and demographics.

Participant recruitment and eligibility

We recruited a total of 130 participants from 20 cities and towns across South Carolina: 65 participants were recruited from independent living in continuing care

retirement communities (CCRCs), which are residential campuses that offer different types of housing and levels of care at the same location [50], and 65 participants were recruited from non-institutional homes. All participants met the following eligibility criteria: female, aged 65 or older, fluent in English, living independently, and self-reported that within the previous 12 months she had experienced a fall leading to a minimum of some type of minor injury, such as a bruise, a cut, or pain, for at least one day. Recruitment occurred from January to March 2015.

Recruitment among CCRCs involved an initial informational message sent via electronic mail or online through the CCRC website to the administrators or members of the marketing department. Two weeks later, at our request, a community liaison from a non-profit organization who works directly with the state's CCRCs reached out to the administrators to confirm the legitimacy of our research and encourage participation. These two initial approaches enabled us to establish good relationships and recruit participants from 10 different CCRCs. In most CCRCs, staff volunteered to obtain a list of all potential participants who met the eligibility criteria and contacted them to assess their interest in completing a brief survey. Staff would then organize an in-person group survey session according to our mutual availability and encourage attendance. In other cases, staff would provide us with the potential participants' information and we would then contact them to schedule an individual survey session. On a few occasions, staff posted our recruitment flyer on their bulletin boards and identified themselves as contacts for more information. Interested potential participants could contact the staff members, who would screen them based on our inclusion criteria before passing along their contact information.

To recruit older women living independently in non-institutional homes, we distributed approximately 300 copies of our recruitment flyer in senior centers, senior apartment buildings, federally qualified health centers, geriatricians' offices, physical therapy clinics, home health agencies, County Councils on Aging, and Area Agencies on Aging across the state. Other recruitment efforts included promoting the research through the state's office on aging website, a local radio show for older adults, social media, and electronic mailing lists of non-profit organizations targeting older adults, church groups, different associations, and word of mouth.

Survey development and pilot testing

We developed a 67-item survey composed of six sections that assessed participants' self-rated health and health literacy (Section A), history and severity of falls (Section B), post-fall changes (Section C), decisional conflict (Section D), familiarity and openness to care options (Section E), and demographic characteristics (Section F). We developed Section C of the survey using our formative qualitative research on older women's responses and decisions after experiencing a fall. We pilot tested the survey with three independent older women who had experienced a fall within the previous year and lived in non-institutional homes. As a result of the pilot testing, we made a few adjustments to increase readability and clarity of the items. For example, one participant explained that "avoid talking about the fall" as a post-fall change could happen once things go back to normal after a fall. We decided to change this item to "avoid telling people about your fall", which focuses more on the immediate and earlier response to a fall rather than a longer-term action. Another item that was improved was "wear an

emergency pendant," which we clarified with "wear an emergency pendant, button, or life alert." We also increased the font size to make the survey easier to read and complete.

Measures

Decisional conflict. In this study, we used decisional conflict as our dependent variable. We assessed whether specific post-fall decisions were associated with decisional conflict using eight out of 16 items adapted from O'Connor's [43] Decisional Conflict Scale; the selected items were the most relevant to post-fall decision making. We asked participants to rate how much they agree or disagree with the following statements, using a 5-point Likert scale from 0 = "Strongly agree" to 4 = "Strongly disagree": "The decision to make this change was easy for me to make;" "I felt I needed more advice and information before making this decision" (reverse-coded); "I felt pressure from others in making this decision" (reverse-coded); "I had the right amount of support from others in making this decision;" "I feel I have made an informed choice;" "My decision shows what is most important for me;" "I expect to stick with this decision and change;" and "I am satisfied with my decision to make this change." We summed all items, divided them by the number of items, and multiplied that number by 25 to get a continuous final decisional conflict score ranging from 0 to 100 , where 0 is no decisional conflict and 100 is high decisional conflict.

Post-fall decision category. We created the variable post-fall decision category based on an open-ended list written by the participants of the top main change they made after experiencing a fall. Initially placed into seven different groups (i.e., decisions about acute treatment/recovery; environment; assistive devices; ambulation; introspection; communication; lifestyle), we collapsed them into three categories: social support;

corrective action; and medical change. We used the medical post-fall decision category as the reference group in our analyses.

Post-fall changes. We provided participants with a list of 34 items or post-fall changes and we asked participants to place a check mark beside all the changes they had made after experiencing their fall(s). Items were based on qualitative research on post-fall decisions and on the falls prevention literature [4; 51; 52]. Examples of such items included: "Go see a doctor?"; "Go to a rehabilitation facility?"; "Remove carpets or rugs?"; "Use a walker?"; and "Avoid telling people about your fall?". We also included an open-ended item where participants could write down a post-fall action or change which was not on the list.

Self-rated health. We used a single item from the revised 12-item Short-Form Health Survey (SF-12) that has been found to be a reliable and valid measure of health status in independent living older adults in retirement communities [53]. The one item is "In general, would you say your health is...Excellent, Very Good, Good, Fair, or Poor?" For analytical purposes, we regrouped the response options into three categories: excellent/very good; good; fair/poor.

Frequency of falls. We measured frequency of falls with one item asking participants "How often have you fallen in the past 12 months?" We provided six different response options: 1 = "Once"; 2 = "A few times in the year"; 3 = "Once every couple of months"; 4 = "Once a month"; 5 = "A few times a month, but not every week"; and 6 = "Every week". We collapsed the responses into two comparable groups: once and more than once.

Severity of falls. We measured respondents severity of falls by asking the following item: "Considering all of your falls in the past year, how severe were your fall(s)?" using a 5-point Likert scale from 1 = "Very minor" to 5 = "Very severe". The five response options were combined into three categories for analytical purposes: very minor/minor; moderate; severe/very severe. Both frequency of falls and severity of falls have been associated with future falls and could possibly be associated with decisional conflict [13].

Health literacy. We assessed health literacy using an adapted version of the following Single Item Literacy Screener (SILS): "How often do you need to have someone help you when you read (and understand) instructions, pamphlets, or other written material from your doctor or pharmacy" [54]. Responses included 1 = "Never", 2 = "Rarely", 3 = "Sometimes", 4 = "Often", and 5 = "Always", where lower scores mean greater health literacy. In the analyses, we reverse-coded the variable so that higher scores represented actual higher health literacy. We also recoded our variable into low health literacy (categories 1-2) and high health literacy (categories 3-5), as recommended by Morris and colleagues [54] and used by other authors [55; 56] and used high health literacy as the reference group. We also used health literacy as a moderator; however, the low variance in health literacy levels made the testing of the moderation effect unfeasible.

Familiarity with care options. We measured familiarity with health and support services and their general knowledge with this item: "Read each statement below and indicate how familiar you are with each of the care options." The three options included adult day care, assisted living, and nursing home, and were followed by a comprehensive definition of each taken from the Department of Health and Human Services [57] and the

National Care Planning Council [58]. Response options were on a 5 point scale ranging from 1 = “I am not at all familiar” to 5 = “I am very familiar.” Response options were collapsed into three groups for the analyses: 1 = "Not familiar" (responses 1 to 3), 2 = "Familiar" (response 4), and 3 = "Very familiar" (response 5).

Openness to care options. We followed the previous question with one item asking participants to think back to the falls that they had experienced in the past year and to indicate how open they would be to accepting the following care options (i.e., adult day care, assisted living, nursing home) if they needed assistance after a fall. Response options were on a 3-point scale, where 1 = "I am not at all open", 2 = "I am somewhat open", and 3 = "I am open". We hypothesized that individuals with less openness to these care options would have greater decisional conflict.

Demographics. We included a range of demographic variables in our study: age, race/ethnicity, marital status, education, living situation, setting (CCRC versus non CCRC), and number of years living in the CCRC, if applicable.

Data collection and analysis

A member of the research team administered the survey in person with all CCRC participants and with more than 75% of non-CCRC participants, and by telephone for the other individuals who lived physically too far for an in-person survey to be easily administered. Each participant first read or was read an information letter describing the study, provided consent to participate, completed the survey, and received \$15 as a compensation for her time and contribution to the research. The survey took on average 20 minutes to complete. We obtained approval of all study documents and protocols from the university's Institutional Review Board prior to the start of data collection.

We used IBM SPSS[®] Statistics 22.0 [59] to analyze the data. We first obtained descriptive statistics using nonparametric frequencies and percentages, and then conducted bivariate analyses using Pearson correlations, t-tests, and one-way analyses of variance. We used a simple ordinary least square regression to test the relationship between the post-fall decision categories (with Medical as the reference group) and decisional conflict (Model 1), followed by multiple regression to assess the effects of familiarity with assisted living, familiarity with nursing home, and health literacy on decisional conflict (Model 2).

Results

Descriptive statistics

Table 1 presents information about the sample of female participants. The mean age of participants was 80.3 years ($SD = 9.2$) and most participants (82%) were white. In the past 12 months, 42% of participants reported falling once and 58% more than once, with answers ranging from a few times in the year (44%) to every week (2%). In terms of health literacy, 92% of participants reported never, rarely, or sometimes receiving help to read instructions, pamphlets or other written material from their doctor or pharmacy; the other 8% of participants needed help often or always, which indicates low health literacy.

[Insert Table 1]

Table 2 presents frequencies of the changes participants made after their falls. Participants reported between 3 and 26 different changes after their falls in the past year, with a mean of 13.5 post-fall changes each ($SD = 5.4$), with no significant differences by fall frequency. The most frequently reported change, “*to be more careful*” was reported by 94% of participants. There were no statistically significant differences in the number

of changes made by women living in CCRCs compared to women living in non-institutional homes.

[Insert Table 2]

Participants were asked to select their top or most important change after their falls based on the list of post-fall changes they had made. In our analyses, we placed these top changes into seven groups, followed by three post-fall decision categories. (See Table 3.) Participants' most important post-fall decision categories were corrective actions (66%), followed by social support changes (24%), and medical changes (10%). The mean decisional conflict score for participants' main post-fall change was 18.4 out of a possible 100, with higher scores indicating greater decisional conflict.

[Insert Table 3]

Bivariate and multivariate analyses

We ran a series of bivariate analyses with all the measures and decisional conflict as the dependent variable (See Table 4). The presence of decisional conflict varied by post-fall decision making category ($p = .04$). Follow-up least significant difference (LSD) tests revealed the medical category differed significantly from the two other post-fall decision categories ($p < .05$). The corrective and social categories did not differ significantly from each other ($p = .24$). Other factors associated with decisional conflict were health literacy, familiarity with assisted living, and familiarity with nursing home ($p < .05$). We used these variables as covariates in our regression models.

[Insert Table 4]

We ran a simple ordinary least square (OLS) regression comparing the Social and Corrective decision categories with Medical as the reference group on decisional conflict.

Results of Model 1 confirmed a statistically significant relationship between post-fall decision category and decisional conflict, where women making social and corrective decisions experienced significantly less decisional conflict compared to the reference group (Table 5, Model 1). In Model 2, we still found a significant difference between the social and medical categories when regressing on decisional conflict, after controlling for the covariates. In addition, women who were not familiar with assisted living felt more uncertainty in their post-fall decision making compared to those who were very familiar ($p = .045$). Women with low health literacy experienced significantly greater post-fall decisional conflict than women with higher health literacy (reference group; $p = .01$). Although we were interested in examining the possible interactions between post-fall decision category and health literacy on decisional conflict, due to the small number of participants that reported having low health literacy we were unable to detect significant interactions by health literacy level. Overall, post-fall decision category, familiarity with assisted living, familiarity with nursing home, and health literacy explained 20% of the total variance in post-fall decisional conflict.

[Insert Table 5]

Discussion and Conclusions

We explored decisions older women made after experiencing a fall, focusing on possible associations between post-fall decision categories and decisional conflict [43]. Our findings suggest that post-fall medical decisions were associated with greater decisional conflict in the decision-making process, compared to corrective and social post-fall decision categories.

Voluntarily making, or being required to comply with an immediate medical decision (i.e., entering a rehabilitation facility) in order to regain her pre-fall physical functions represents an important change in an older woman's life [30; 60]. Making this type of decision may cause older women greater decisional conflict, given that the decision may not be welcomed or may represent a loss of independence, self-esteem, and quality of life [61]. However, given the immediate and imperative nature of medical decisions (e.g., hip fracture) the decision may not represent a personal choice.

Uncertainty in post-fall decision-making may result from not having adequate knowledge and information about the next steps, as well as feeling unwanted pressure from others in making this decision [44]. When an older woman associates her quality of life with good physical health and regular participation in programmed social activities, suddenly having to focus on post-fall physical injuries and new fears and worries resulting from the fall constitute an added workload of getting back to normal [30; 62].

In this research, the older women who reported making other types of post-fall changes (i.e., decisions made under the social support and corrective action categories) had lower decisional conflict. Several factors may help explain this finding. First, these changes are comparatively less disruptive to the women's lives than making medical changes after a fall. There is an important difference in the severity and the impact of the change between being in a rehabilitation facility for three months to recover from a hip fracture repair (medical) versus wearing a life alert button (social) or removing rugs in the home (corrective).

Second, social support related decisions – including getting help from others for bathing, asking family to check up on her, bringing the cell phone with her when she goes

out of the house – are all decisions relating to the provision of assistance. These types of decisions may actually help reduce stress and fear related to the fall and any future falls [63; 64], help women cope with the consequences of the fall [66], and may provide a sense of safety and security to continue engaging in regular activities [64; 66; 67]. These types of decisions appear to be easier to make due to this support from others and to the communication surrounding decision making.

Alternatively, decisions to take corrective actions after the fall – including installing a night light, using a walker, picking up her feet, and sleeping in the middle of the bed – are decisions that do not appear to be as time-sensitive as medical decisions. They can be effective temporary solutions for addressing the causes of the fall, including poor lighting and balance impairment, and for preventing recurrent falls [68-70]. In this study, the lower levels of decisional conflict in relation to these types of decision may have been associated with higher levels of perceived control over these types of corrective actions and the ability to consult others if necessary, which could explain lower decisional conflict in making these types of decisions.

Similar to findings from previous studies [47-49], health literacy was a strong predictor of decisional conflict among this sample of older women. Our results showed that participants with lower levels of health literacy experienced greater decisional conflict in making post-fall decisions. Other researchers have found that individuals with higher health literacy skills have greater knowledge and understanding of health conditions and their management, consult and follow-up with their doctors, and feel more confident in their ability to follow and adhere to public health recommendations (e.g., taking medications or physical therapy) when compared to individuals with lower health

literacy [71-74]. When making post-fall decisions, older women with higher health literacy may better understand the importance of preventing future falls by picking up their feet (i.e., making a corrective action decision) or getting help from others to recover as quickly as possible (i.e., making a social support decision). Women with higher health literacy may have higher levels of information seeking skills and better access to information from various sources. Examples would be reading brochures about life alert buttons, obtaining fall prevention information at a medical facility, and seeking answers to personal inquiries by discussing issues with health professionals, family, and friends. Actively seeking other information sources in the process of making post-fall decisions may contribute to decreased decisional conflict [75; 76].

The findings of this research are applicable to educational interventions aimed at assisting older women in general, and particularly those with lower health literacy, in anticipating and actually making post-fall decisions. One aim of educational and supportive interventions should be to decrease tension and uncertainty in post-fall decision-making. Information on the range and implications of possible decisions should be provided at appropriate reading levels. It is also important for health educators and healthcare and social service professionals to provide plain language information on the broad range of possible decisions that can be made after a fall. There is a need for targeted decision aids for low-literate and low-health literate groups that address the potential conflicts older women may experience in making post-fall decisions. Such resources can contribute to increasing older women's knowledge about different options, decreasing their decisional conflict, and helping them make more informed decisions [48; 77; 78].

Health professionals, family members, and care providers involved in the women's post-fall experience should also be informed of the possibility of women experiencing greater decisional conflict in relation to medical decisions. Potential interventions include directed communication and education regarding the implications and importance of these types of medical interventions in promoting prompt and optimal post-fall recovery. It is probable that the higher the level of satisfaction with the primary post-fall decision, the less decisional conflict a woman will experience. In turn, lower decisional conflict may enhance post-fall recovery and the potential for maintaining her desired quality of life.

This research produced some unexpected results. The survey initially contained a list of 34 post-fall changes; however, participants added more than 90 other post-fall changes (e.g., refraining from driving a vehicle, letting the phone ring, elevating their injured foot, asking for prayers, letting others know where they are going) in their open-ended responses. We were expecting group differences in the total number of post-fall changes made by living situation (i.e., CCRC versus non-CCRC), race (White versus Black participants), and frequency of falls (one fall versus more than one fall), but these differences were not found. The findings also suggest that within our diverse sample of older women, participants made more than 10 changes after a fall.

Limitations include the cross-sectional design, which did not allow any causal attributions, and the limited range of health literacy among the sample, with only 11 of the 130 participants reporting low health literacy. This lack of variance precluded our ability to assess the role of health literacy as a moderator in the conditional direct effect of post-fall decision category on decisional conflict. A possible contributing factor to this

lack of variance may have been the high level (91%) of participants recruited from CCRCs with a high educational attainment level (i.e., some college or higher) [79]. It is also possible that older women may have overestimated their levels of health literacy or simply under reported the help they receive reading materials from their doctor or pharmacy [79; 80].

This research was innovative in its aim to explore the phenomenon of post-fall decision making among older women. The findings emphasized the breadth of decisions, including health, independence, and quality of life, and the importance of health literacy in post-fall decision making. Post-fall decision making clearly warrants recognition and inclusion as a crucial component in the falls prevention literature.

This survey could also be developed further to include other aspects of post-fall management including medication, chronic disease management, and fear of falling. Similar research is needed to explore post-fall decision-making among older men. Future research should also consider recruiting a larger sample of older women to conduct more complex statistical analyses on post-fall decision making. For older women and their care providers, these findings should serve as a resource for falls prevention and management efforts.

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Table 4.5: Participant Demographics, *N*=130

Sample Characteristics	Frequency (%)	Mean (SD)	Range
Age (years)		80.3 (9.2)	65-99
Race/Ethnicity			
White, non Hispanic	107 (82.3%)		
Black, non Hispanic	23 (17.7%)		
Marital status			
Widowed	72 (55.4%)		
Married/Living with partner	28 (21.5%)		
Divorced/Separated	22 (17.0%)		
Single/Never married	8 (6.2%)		
Education ^a			
High school education or lower	29 (22.3%)		
Some college	32 (24.6%)		
Bachelor's degree	33 (25.4%)		
Graduate degree	36 (27.7%)		
Living situation			
Living by herself	92 (70.8%)		
Living with spouse/partner	28 (21.5%)		
Other (e.g., pet, adult child, caregiver)	10 (7.7%)		
Years living in CCRC		7.3 (5.9)	0.8-27
Frequency of falls in the past 12 months			
Once	55 (42.3%)		
More than once ^b	75 (57.7%)		

^a Participants living in a CCRC had more education than those living in non-institutional homes ($X^2(3, 129) = 16.323, p = .001$).

^b For participants who reported falling more than once, their answers ranged from falling a few times in the year (43.8%) to every week (2.3%).

Table 4.5 (continued): Participant Demographics, *N*=130

Sample Characteristics	Frequency (%)	Mean (<i>SD</i>)	Range
Severity of falls in the past year			
Excellent/Very good	61 (46.9%)		
Good	42 (32.3%)		
Fair/Poor	27 (20.7%)		
Health literacy			
Low	11 (8.5%)		
High	119 (91.5%)		
Familiarity with care options^c			
Adult day care ^d	111/130 (85.3%)		
Assisted living	122/130 (94.0%)		
Nursing home	123/130 (94.6%)		
Openness to care options^e			
Adult day care	60/130 (46.2%)		
Assisted living	60/130 (46.2%)		
Nursing home ^f	44/130 (33.8%)		
Decisional conflict^g		18.4 (13.8)	0-87.5

^c Response categories combined are "Very familiar" and "Familiar". Other response categories included "Neither familiar nor not familiar", "Not familiar", and "Not at all familiar".

^d Participants living in a CCRC were less familiar with adult day care than those living in non-institutional homes as there are similar activities organized in the CCRC setting ($X^2(4, 129) = 9.340, p = .053$).

^e Response category shown is "Being open". Other categories included "Somewhat open" and "Not open".

^f Participants living in a CCRC were more open to moving to a nursing home if they needed assistance after a fall compared to participants living in non-institutional homes ($X^2(2, 129) = 6.952, p = .031$).

^g Higher scores represent greater decisional conflict.

Table 4.6: Frequency of Post-Fall Changes, *N*=130

Post-Fall Changes	Frequency (%)
Be more careful	122 (93.8%)
Look where walking	113 (86.9%)
"Other" ^a	97 (74.6%)
Hold on when walking	91 (70.0%)
Slow down	89 (68.5%)
Pick up feet	88 (67.7%)
Avoid places with fall risk	86 (66.2%)
Go see a doctor	83 (63.8%)
Get help from God	73 (56.2%)
Take pain medication	72 (55.4%)
Get more rest	71 (54.6%)
Get help from others	65 (50.0%)
Drink more water	60 (46.2%)
Exercise inside of home	59 (45.4%)
Exercise outside of home	56 (43.1%)
Use a cane	54 (41.5%)
Take more breaks when walking	54 (41.5%)
Use a walker	53 (40.8%)
Do physical therapy	49 (37.7%)
Use a shower seat or raised toilet seat	38 (29.2%)
Use hand grip reachers	31 (23.8%)
Remove carpets	30 (23.1%)
Avoid telling people about the fall	30 (23.1%)
Change shoes	29 (22.3%)
Wear an emergency button	29 (22.3%)
Get a home assessment	26 (20.0%)
Use a night light	26 (20.0%)
Use a wheelchair	19 (14.6%)
Go to a rehabilitation facility	17 (13.1%)
Avoid getting help from others	17 (13.1%)
Install handrails	11 (8.5%)
Drink less alcohol	9 (6.9%)
Use pull cords	6 (4.6%)
Use a lift chair	3 (2.3%)
Install bed rails	1 (0.8%)

^a "Other" included decisions like putting ice on the injury, stop driving temporarily, letting others know where they are going, eating healthy, walking with the heel first, avoiding getting up too fast, bringing the phone with them in the house, discontinuing their medication, removing objects on the floor, accepting their condition, etc.

Table 4.7: Frequency of Main Post-Fall Decision by Group and Category, *N*=130

Group	Category	Frequency (%)
Environment (e.g., remove carpets) Assistive devices (e.g., use a walker) Ambulation (e.g., be more careful) Introspection (e.g., accept your condition) Lifestyle (e.g., exercise)	Corrective action	86 (66.2%)
Communication (e.g., get help from others)	Social support	31 (23.8%)
Acute treatment/Recovery (e.g., go see a doctor)	Medical change	13 (10.0%)

Table 4.8: All Measures by Decisional Conflict, $N=130$

Sample Characteristics	Decisional Conflict
	Mean (<i>SD</i>) or <i>r</i>
Post-fall decision category ^b	
Social support	15.02 (12.11)
Corrective action	18.35 (11.27)
Medical change	26.44 (26.16) [*]
Number of post-fall changes ^a	0.01
Self-rated health ^b	
Excellent/Very good	16.85 (12.68)
Good	19.79 (16.26)
Fair/Poor	19.56 (12.18)
Frequency of falls in the past 12 months ^c	
Once	20.28 (15.72)
More than once	16.96 (12.15)
Severity of falls in the past year ^b	
Very minor/Minor	18.52 (10.79)
Moderate	16.44 (12.56)
Severe/Very severe	20.67 (17.64)
Health literacy ^c	
Low	29.83 (11.47) ^{**}
High	17.31 (13.57)
Familiarity with adult day care ^b	
Not familiar	22.86 (20.33)
Familiar	19.12 (13.26)
Very familiar	15.27 (10.47)

^a Pearson correlation, ^b F test, ^{*} Bonferroni adjustment: $p<.0025$, ^c t-test, ^{**} $p<.01$

Table 4.8 (continued): All Measures by Decisional Conflict, $N=130$

Sample Characteristics	Decisional Conflict Mean (<i>SD</i>) or <i>r</i>
Familiarity with assisted living ^b	
Not familiar	28.52 (22.50)*
Familiar	20.93 (15.15)
Very familiar	14.96 (10.00)*
Familiarity with nursing home ^b	
Not familiar	23.21 (15.51)
Familiar	22.73 (16.77)*
Very familiar	14.34 (9.20)*
Openness to adult day care ^b	
Not at all open	15.88 (11.61)
Somewhat open	20.55 (19.59)
Open	18.70 (10.95)
Openness to assisted living ^b	
Not at all open	14.58 (12.07)
Somewhat open	18.53 (14.65)
Open	19.95 (13.82)
Openness to nursing home ^b	
Not at all open	18.13 (13.38)
Somewhat open	18.84 (17.03)
Open	18.25 (13.81)
Age ^a	0.11
Race/Ethnicity ^c	
White, non Hispanic	18.81 (14.04)
Black, non Hispanic	16.30 (12.78)

^a Pearson correlation, ^b F test, ^{*} Bonferroni adjustment: $p < .0025$, ^c t-test, ^{**} $p < .01$

Table 4.8 (continued): All Measures by Decisional Conflict, $N=130$

Sample Characteristics	Decisional Conflict Mean (SD) or r
Marital status ^b	
Widowed	19.44 (12.45)
Married/Living with partner	20.76 (18.66)
Divorced/Separated	11.93 (10.94)
Single/Never married	17.97 (8.80)
Education ^b	
High school education or lower	21.01 (12.58)
Some college	16.99 (14.50)
Bachelor's degree	16.95 (11.43)
Graduate degree	18.75 (16.16)
Living situation ^b	
Living by herself	17.36 (12.15)
Living with spouse/partner	20.98 (19.03)
Other (e.g., pet, adult child, caregiver)	20.31 (10.95)
Setting	
CCRC	17.64 (11.07)
Non-institutional home	19.09 (16.15)
Years living in CCRC ^a	0.06

^a Pearson correlation, ^b F test, ^{*} Bonferroni adjustment: $p<.0025$, ^c t-test, ^{**} $p<.01$

Table 4.9: Ordinary Least Square Regression Models Predicting Decisional Conflict, Unweighted Data ($N=130$)

Decisional Conflict	Model 1		Model 2	
	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>
Post-Fall Decision Category (reference: Medical)				
Social	-11.42*	4.49	-10.06*	4.26
Corrective	-8.09*	4.04	-7.41	3.84
Familiarity with Assisted Living (reference: Very Familiar)				
Not familiar with assisted living			11.33*	5.68
Familiar with assisted living			0.75	3.14
Familiarity with Nursing Home (reference: Very Familiar)				
Not familiar with nursing home			2.93	6.04
Familiar with nursing home			6.12	3.19
Low Health Literacy (reference: High Health Literacy)			10.63*	4.18
Model 1: $F(2, 127) = 3.241, p = .042; R^2 = .049, *p < .05$				
Model 2: $F(7, 122) = 4.431, p = .000; R^2 = .203, *p < .05$				

CHAPTER 5

CONCLUSIONS AND IMPLICATIONS

The goal of my dissertation was to better understand post-fall decision making among older women living in CCRCs. To meet this goal, I explored the meanings of falls (RQ1), the decisions older women make after their falls (RQ2), and the involvement of others in the post-fall decision-making process (RQ3-RQ6). I also examined intrapersonal factors that influence post-fall decision making including self-rated health, history of falls, severity of falls, health literacy, familiarity and preferences with care options, and decisional conflict (RQ7-RQ9). In this chapter, I review the results of each research question. I also discuss the implications of the study as well as ideas for future research.

Research Question 1: What meanings do older women residing in CCRCs associate with their experience of a fall?

All 17 women interviewed in this study reported that their falls were unexpected events. They happened suddenly, without any warning, and left such an impact on their lives that the women could make a clear distinction between before and after the fall. A fall was predominantly perceived negatively. Women expressed feeling angry, embarrassed, stupid, shocked, and helpless after a fall. All of these different emotions could really affect the women's self-perceptions and identity.

In most cases, experiencing a fall made the women more aware of four important aspects of their lives: their physical, emotional, spiritual, and social health. All of their approaches and decisions when managing their falls focused specifically on re-establishing or valuing their physical, emotional, spiritual, and social independence.

The women's emotional health, however, was particularly important after a fall. All but a handful of participants reported worrying after the fall. This work of worry (Messias et al., 1997) was part of all decisions including avoiding public attention because of the fall, deciding to get help from others, and managing this new fear of falling. These results are consistent with other research on the meaning of falls (Dollard, et al., 2012; Hanson, Salmoni, & Doyle, 2009; Høst, et al., 2011; Stewart & McVittie, 2011), fear of falling (Boyd & Stevens, 2009; Calhoun, et al., 2011; Høst, et al., 2011; Patil, et al., 2014; Roe, et al., 2008; Zijlstra et al., 2007), and the impact of a fall on one's self-identity (Ballinger & Payne, 2002; Dollard, et al., 2012; Hanson, et al., 2009; Høst, et al., 2011; Stewart & McVittie, 2011).

Considering that one in three older women experiences a fall every year (Centers for Disease Control and Prevention, 2015a; Lord, Sherrington, Menz, & Close, 2007), it is important to work toward normalizing falls and reducing the stigma surrounding them (Hanson, 2010; Schneider and Beattie, 2015). The more we can recognize that falls are not a death sentence but rather an opportunity for positive change, the more women will avoid concealing information about their falls, and subsequently be able to discuss them with others and make informed decisions to regain their health and quality of life (Hanson, 2010). This normative shift in attitudes surrounding a fall is needed not only among older women, but also among family members and professionals.

Research Question 2: What decisions do older women residing in CCRCs make after a fall and what are the outcomes of those decisions?

Older women residing in CCRCs took one or more approaches to "get back to normal" after their falls, which subsequently led to different post-fall decisions (as described in Manuscript 1). These approaches included assessing their personal physical and emotional needs in the context of the work of recovery; feeling burdened by the extra work of getting back to normal; seeking and getting assistance; avoiding specific people, objects, and places; being proactive; and putting the fall out of mind. Depending on the approach, several post-fall decisions were made, such as going to see a doctor, taking pain medication, imposing self-limitations, engaging in rehabilitation or physical therapy, temporarily adjusting their routine, being more careful, using a walker, contracting temporary help, soliciting support from God, avoiding any type of assistance, wearing a life alert system, and not being in a hurry anymore, among others. The approach(es) women took after their falls and the decisions they made concurrently would determine their future health outcomes towards recovery or towards long-term disability.

In their study of 14 older adults who visited the emergency department after a fall, Høst and colleagues (2011) found similar strategies to cope with the consequences of their fall, including engaging or not in certain activities and obtaining support from their social network. The main differences between Høst et al.'s study (2011) and the first phase of my dissertation research are that I looked specifically at older women, as they experience greater incidence of falls in older adulthood (Rossat, et al., 2010; Schiller, et al., 2007; Stevens & Sogolow, 2005; World Health Organization, 2007), and I focused only on women living in CCRCs.

The different approaches women used after a fall deserve greater attention. Fowler and colleagues (2015) reported in a recent study that older adults' attitudes and communication impact healthy aging; accordingly, if an older woman categorizes herself as "old" all of a sudden because of her fall, and communicates her loss of optimism and confidence in her daily activities, she may express a negative attitude toward her aging process, which will indirectly limit her ability to get stronger and engage in fall prevention measures (Bell & Menec, 2015; Fowler, et al., 2015). In fact, Nyman (2011) indicated that older adults who felt responsible for their fall (i.e., attributed their fall to an internal and unpreventable cause) were less likely to engage in falls prevention programs compared to those who attributed it to an extrinsic factor (e.g., the weather).

The post-fall approach of avoidance can also have negative consequences on a woman's health. Avoiding help from others, avoiding disclosure of the fall, or staying away from areas where she might fall may all lead to a sedentary lifestyle (Clemson, et al., 2015; World Health Organization, 2007), social isolation (Bell & Menec, 2015; Clemson, et al., 2015; World Health Organization, 2007), depression (Ball et al., 2004; Biderman, Cwikel, Fried, & Galinsky, 2002; Clemson, et al., 2015; World Health Organization, 2007), frailty (Ahmed, Mandel, & Fain, 2007; World Health Organization, 2007), loss of independence (Ball, et al., 2004; World Health Organization, 2007), and a downward spiral in health (Ahmed, et al., 2007).

In contrast, the approach of putting the fall out of mind may temporarily help the woman's emotional health and personal identity by not worrying about falling (Hanson, et al., 2009). Unfortunately, it does not lead one to reflect and learn from the

event and to prevent recurrent falls through home modifications and/or physical conditioning (Centers for Disease Control and Prevention, 2008; Roe, et al., 2008).

This study enabled a greater understanding of the array of approaches and decisions older women residing in CCRCs take after experiencing a fall. These findings can help health care professionals, CCRC staff, and family and friends understand the logic behind specific decisions older women make after a fall, and adjust their communication and actions accordingly when providing support to an older woman who has fallen. In addition, this study can help women in these types of situations to be more aware of different options that are available to them after a fall, which can hopefully guide them toward better, healthier post-fall decision making, ultimately leading to recovery, health, and quality of life.

Research Question 3: Who or what do older women residing in CCRCs identify as their main sources of information when making post-fall decisions?

Older women's main sources of information after a fall were professionals and family members. Professionals included CCRC staff and health care providers such as geriatricians, dentists, and physical therapists. Family members included husbands and adult children. Although other residents and extended family were also sources of information, older women did not involve them as much in their post-fall decision making as professionals and immediate family.

Very few women living in CCRCs mentioned the media as a source of information for post-fall decision making. Some talked about television and books; none of the women interviewed mentioned using the internet as a source of information after their fall, in part due to limited internet access in the CCRCs. These findings are

consistent with a study from Chaudhuri and colleagues (2013) who assessed information sources of older adults living in 11 different retirement communities in the state of Washington. Residents' information sources were ranked in order of preference from health care providers, friends, relatives, and CCRC staff and finally to the internet, television, and the radio (Chaudhuri, et al., 2013). Other studies also confirmed that older adults use primarily members of their social network for decision making including doctors (Arora & McHorney, 2000; Brown, Carroll, Boon, & Marmoreo, 2002; Burns, Jones, Iverson, & Caputi, 2013; Chaudhuri, et al., 2013; Hesse, et al., 2005; Levinson, et al., 2005; Williamson & Asla, 2009) and family members (Brown, et al., 2002; Chaudhuri, et al., 2013; Gallant, Spitze, & Prohaska, 2007; Williamson & Asla, 2009).

Research Question 4: What type of information and advice do these sources provide?

Although both professionals and family members wanted to provide older women with information and advice about how to treat their injuries, manage their falls, and prevent future falls, the women's relationship with these sources influenced whether such information was shared. Older women had open, direct, and formal relationships with professionals. The women would ask their sources for information and recommendations about rehabilitation, medication management, their return home, exercising, specific ambulation techniques, and about what to do next.

Some family members had an open and honest relationship with the women and could therefore bring up a topic related to their fall, discuss different potential options and costs to manage the cause of the fall, and really be involved in the women's decision-making process. Some older women would even rely entirely on the family member or professional and take their suggestion as their final post-fall decision.

In more than half of all cases with family members as sources of information, however, women did not have a good, open relationship with their husbands or adult children, which led the women to refrain from taking advice from these individuals. To share advice about how to be more stable on their feet or to prevent future falls, family members weighed their words and used humor to make a suggestion. Some family members even avoided bringing up the topic of the fall so as not to hurt the women's feelings.

Several researchers have examined these complex communication patterns that exist between older women and their adult children (Cicirelli, 2003; Edwards & Chapman, 2004a, 2004b; Fingerman, 2001; Hay, et al., 2008; Pecchioni, 2001). It is important to learn how to develop open communication patterns to discuss these issues in older adulthood. Such communication patterns include being assertive and honest, trusting each other, clearly expressing one's thoughts and feelings, and asking for help and being willing to receive help (Peterson & Green, 2009; Smith, 2012). Following these guidelines, a woman and her family member can work together to make the best post-fall health decisions possible.

Research Question 5: How do older women residing in CCRCs assess the quality, credibility, and trustworthiness of these sources when making post-fall decisions?

Older women generally assessed the quality, credibility, and trustworthiness of their information sources through their credentials and formal education. They tended to perceive professionals as credible, trustworthy and knowledgeable sources of information. They were willing to discuss their falls with these sources and listen attentively to the sources' advice. This finding is consistent with previous studies on older

adults and trusted sources for health related questions, which indicated that health professionals were the most trusted sources of general health information (Chaudhuri, et al., 2013), sources of information on prescription drugs (Donohue, Huskamp, Wilson, & Weissman, 2009), and of cancer information (Friedman & Hoffman-Goetz, 2003).

On the other hand, older women in this dissertation research perceived family members as trustworthy individuals considering their shared long-standing relationships, but they were not considered the most credible sources of information after a fall. This lack of credibility impacted how much family members could be involved in women's post-fall decision making. These findings that family members are trusted sources of information but not the primary sources are supported by studies from Chaudhuri and colleagues (2013), and Morey (2006), among others.

Research Question 6: If a person is identified as the older woman's main source of information, how does this person view his/her role in the older woman's post-fall decision making?

The 11 secondary informants that were interviewed in the first phase of this study reported on their roles in older women's post-fall decision-making processes. Professionals viewed their roles mostly as a source of information. They provided information and advice to the women, answered their questions, helped them evaluate different options during their shared decision-making processes, and assisted in making the final decision. Some family members were also involved in this direct information exchange by looking up information, discussing options, and offering advice.

Most family members and some professionals also took on additional responsibilities that go beyond this traditional sender-receiver communication model.

These sources were available and willing to help the women at any time. They provided the women with tangible and instrumental assistance while they were making these post-fall decisions (e.g., driving them to the doctor's office). More importantly, these secondary informants were offering emotional support and encouragement to the women throughout the decision-making process.

Although the sources' involvement in the actual decision making varied greatly based on the women's openness to reliance on others, their assessment of the source's credibility, and their established relationship patterns (as described in Manuscript 2), the role of the secondary informants was not limited to informational support.

This research question provided an interesting brief look at the impact falls can have on family members. In their critical narrative literature review, De la Cuesta Benjumea and Roe (2015) found that very few studies explored how the social and family context impacts the fall experience, and specifically how a fall can impact the health and quality of life of those close to the person who has fallen. Future research should further explore family members' role in the post-fall experience.

Research Question 7: How are older women's self-rated health, history of falls, severity of falls, and health literacy associated with their post-fall decision making?

In Phase 2 of the study, I examined how different intrapersonal factors were associated with post-fall decision making. The variable post-fall decision making was measured with decisional conflict (O'Connor, 1993, 1995), where a higher score represented greater uncertainty in making the women's top post-fall decision or change. While self-rated health, history of falls, and severity of falls are all risk factors for falls (Ambrose, et al., 2013; LeBouthillier, Thibodeau, & Asmundson, 2013; Patil, et al.,

2014), none of these variables were associated with post-fall decisional conflict in the bivariate analyses. In other words, self-rated health, history of falls, and severity of falls were not found to play a role in decision making after a fall.

Conversely, health literacy was associated with decisional conflict ($p = .012$), where older women with higher health literacy experienced lower decisional conflict when making post-fall decisions. Health literacy also appeared to mediate the relationship between the three main post-fall decision categories and decisional conflict, but the majority of participants (92%) had adequate health literacy skills, as measured by the Single Item Literacy Screener (Morris, et al., 2006), which made it difficult to examine an interaction by health literacy (low and high health literacy).

Our results show that health literacy impacts post-fall decision making. Greater health literacy is directly associated with better decision making (James, Boyle, Bennett, & Bennett, 2012), better health status and less hospitalization and emergency room visits (Cho, Lee, Arozullah, & Crittenden, 2008; Safeer & Keenan, 2005). As physicians commonly overestimate their patients' health literacy levels (Kelly & Haidet, 2007), it is important to (1) provide plain language falls prevention and medical information to older women and their families to help decrease decisional conflict when making post-fall decisions; and (2) ensure that health care providers also assess patients' recall and comprehension of new health information to ensure that older women understand the information and advice provided and can use that information in their decision making (Schillinger et al., 2003). Offering plain language information to the public (i.e., older adults, families, professionals) on the range of possible post-fall decisions would be ideal to facilitate informed decision making before and after a fall.

Research Question 8: How are older women's familiarity with care options and openness to care options associated with their post-fall decision making?

I assessed older women's familiarity with care options using three items on the exploratory survey, i.e., one item for each care option: adult day care, assisted living, and nursing home. I also assessed women's openness to these care options with three survey items asking whether the women would be open, somewhat open, or not at all open to these care options if they needed assistance after a fall. Results of the one-way analysis of variance showed that decisional conflict was associated with older women's familiarity with assisted living ($p = .005$). Posthoc analyses revealed that those who were very familiar with assisted living had less decisional conflict compared to the other groups (familiar: $p = .040$; not at all to neither familiar nor familiar: $p = .021$). I found similar results with familiarity with nursing home, where those who were very familiar with nursing home had less post-fall decisional conflict than those who indicated being familiar with this care option ($p = .002$). The rest of the variables (i.e., familiarity with adult day care and openness to these three options) did not yield any significant associations with post-fall decision making. In the OLS multiple regression, however, only familiarity with assisted living remained a significant predictor of decisional conflict, where those who were not familiar with assisted living experienced significantly greater decisional conflict compared than those who were very familiar with assisted living ($p = 0.05$).

Previous studies have indicated that greater knowledge or familiarity with different care services leads to greater preparation for future care needs (Delgado, Sörensen, & Coster, 2004; Sörensen & Pinquart, 2001). Engaging in the preparation

process also brings about informed decision making (Sörensen & Pinquart, 2001).

Increased knowledge of any long-term care option may help reduce older women's uncertainty in the post-fall decision-making process.

Research Question 9: How are older women's post-fall decisions associated with decisional conflict?

The post-fall exploratory survey results suggested that post-fall decisions, which we placed in three different categories (i.e., social support, corrective action, and medical change) were significantly associated with decisional conflict ($p = .018$). Post-hoc analyses showed that the post-fall medical category was significantly different than the social support and corrective action categories, where older women making post-fall decisions from the medical category experienced far greater uncertainty compared to other types of post-fall decisions and changes. Greater decisional conflict when making post-fall medical decisions may be explained by the disruptive and immediate nature of these decisions. Women making decisions from the social support category had the lowest decisional conflict scores. Older women's decisional conflict could be reduced through greater education, consultations, and information about post-fall decisions and health care options for them and for members of their social networks, including health care professionals and family members (Collins et al., 2009; O'Connor, et al., 2002). Using decisional aids may also help older women making medical decisions engage in the post-fall decision-making process with greater confidence (Lewis, et al., 2010; Montori, et al., 2011; O'Connor, et al., 2002; Schonberg, et al., 2014; Stacey, et al., 2012; Stacey, et al., 2014; Wong, et al., 2012).

Implications for Practice

The results of this dissertation demonstrate the importance of better understanding the decision-making process after a fall. Such understanding can help older women make informed decisions that will help them recover from their fall injuries, regain their health and quality of life, and prevent future falls. This research has several important implications for older women, members of their social networks, and falls prevention experts and policy makers.

First, older women need to be made aware of the broad range of approaches and decisions that others have taken after a fall. This can help them consider different options, ask more questions, and make the best decisions about their health. They also need to learn the importance of communicating after a fall and reaching out for information and decisional support. Survey results indicated that women who made decisions from the social support post-fall decision category (e.g., getting help from others; telling her daughter where she is going; bringing the phone with her in case of an emergency) experienced the least amount of decisional conflict among all three groups of post-fall decision category. This suggests that being open and accepting of some type of help from others after a fall can decrease the anxiety associated with managing this important life event.

The results of this study also have great implications for any type of professional working with older women, including geriatricians, physical therapists, social workers, nurses, home care workers, and CCRC staff. These professionals are seen as credible sources of health information and decision-making assistance. They can play a key role in conducting pre-fall assessments. This would include: discussing falls and

assessing the women's fall risks; proactively identifying potential information sources in the post-fall decision-making process; and having an open discussion about different post-fall approaches and decisions to manage fall situations and prevent future falls. Similarly, professionals can conduct post-fall assessments, which would include asking older women if they have fallen (Centers for Disease Control and Prevention, 2015e), and educating them on important medical decisions that may lead to greater decisional conflict when making these types of decisions. Professionals should engage in this discussion respectfully and consider using decisional aids to convey health information (Lewis, et al., 2010; Montori, et al., 2011; Schonberg, et al., 2014; Wong, et al., 2012). This discussion has the potential to increase older women's knowledge of post-fall decision making and help the woman and her professional establish a shared decision-making process, which can lead to improved decision making after a fall.

Professionals should engage in this discussion respectfully and can also use decisional aids to help convey the information (Lewis, et al., 2010; Montori, et al., 2011; Schonberg, et al., 2014; Wong, et al., 2012). This discussion has the potential to increase older women's knowledge of post-fall decision making and help the woman and her professional establish a shared decision-making process, which can lead to improved post-fall decision making.

Family members also play a crucial role in this post-fall decision-making process. As indicated for professionals, family also needs to focus on raising awareness and communicating these important results. Family may also benefit from understanding the different approaches older women may take after a fall, and why they may or may not rely on others for help in decision making. Family members can help women in this

vulnerable state by trying to establish an open and honest conversation about the fall, all with the goal of maintaining the women's independence.

This research has major implications for fall prevention experts and policy makers. These results revealed that post-fall decision making was an understudied complex phenomenon that truly influences older women's health and quality of life. The decisions older women make after a fall can determine if and how they will recover from a fall and prevent repeat falls. Post-fall decision making should be included in falls prevention intervention efforts and policies so that this important part of the fall experience is considered, valued, and used to help with the prevention and management of falls among older women.

Finally, as previously indicated in Research Question 1, a change at the societal level is needed to reduce the stigma associated with falls (Hanson, 2010; Schneider and Beattie, 2015). As society views falls negatively, most older women feel embarrassed when they experience a fall and therefore keep information about their fall private. They try to distance themselves from potential ageist stereotypes associated with the fall (e.g., being seen as old and feeble) and use different strategies such as avoiding to talk about their fall to reduce their stigmatized status (Hanson, 2010). Culture may also play a role in this stigma, depicting falls as unavoidable events in older adulthood and promoting rather sedentary lifestyles among older adults, which increases their risks of falling (World Health Organization, 2007).

Several steps can be taken to reduce the stigma associated with falls. First, disseminating positive images of older women recovering after a fall could help women and members of their social network understand that it is possible to "*get back to normal*"

after a fall. Second, talking about falls as much as possible and addressing falls directly can help women be more open to sharing their experiences, which can then improve the normalization of falls (Hanson, 2010). Community discussions about falls could also be organized to discuss these important issues of privacy and disclosure after a fall, which could help reduce its associated stigma. Conducting home assessments and focusing on safety measures (e.g., installing grab bars and removing rugs) could be done proactively to prevent a fall, and therefore not be associated with "old age" once an older woman experiences a fall (Centers for Disease Control and Prevention, 2012). Finally, as cancer screenings are recommended as people age (e.g., breast cancer screening, colorectal cancer screening), public health practitioners and organizations could also strongly recommend that both middle-aged and older adults take part in falls prevention programs. Older adults' participation in these programs could lead to greater prevention and communication about falls.

Implications for Future Research

Several aspects of this study could be examined differently in future research. First, in the post-fall interviews, a distinction could have been made to compare how post-fall decision making differs for first-time fallers versus recurrent fallers. Due to the small sample size of the interviewees, this was not done; however, such a distinction could increase knowledge of the decision-making process by (1) examining how decision making evolves with a history of falls, and (2) possibly even extending the reach of our results to those who have not yet fallen (based on the interviews with the first-time fallers) in the hopes of helping them prevent future falls.

To keep this dissertation manageable, I opted to interview independent women residing in CCRCs. I was therefore looking to explore the role of CCRC staff as well as find post-fall decisions that would be specific to this setting (e.g., wearing a life alert to notify staff of a fall). In the future, researchers could also conduct interviews with independent older women living in non-institutional homes, and compare the results to this study.

I limited my second set of interviews to one source per older woman, interviewing a total sample of 11 secondary informants due to some primary informants not having a source of information after a fall and to others refusing to put me in contact with their source. Considering that decision making is often made with a constellation of sources (Shawler, et al., 2001), future research on this topic should include interviews with more than one source per older woman to obtain a more comprehensive description of the shared post-fall decision-making process.

Future researchers on falls could make important revisions to the exploratory post-fall survey used in my dissertation research. First, they could include a better definition of severity of falls, as participants had difficulty assessing the severity of their falls in the past 12 months without a proper definition. Second, they could examine fear of falling and falls efficacy to see how these factors influence decisional conflict (Hübscher, Vogt, Schmidt, Fink, & Banzer, 2010; Kempen et al., 2008). They could use a more plain language version of the Decisional Conflict Scale to facilitate data collection on the dependent outcome (Linder et al., 2011). In addition, future researchers could use a mini-mental state assessment such as the Montreal Cognitive Assessment (MoCA) in all phases of the study to properly assess participants' cognition levels (Horton et al.,

2015). This exploratory survey has the potential to be developed into a full post-fall decision-making survey that can be used among older adults in CCRCs and other settings across the country and abroad.

This entire study could be repeated with older men (either living in CCRCs or non-institutional homes) to explore their experiences after a fall and to examine their decision-making processes. Similarly, a study of post-fall decision making among middle-aged adults may help decrease the incidence of falls as people age (Caban-Martinez et al., 2015; Ory et al., 2014).

Finally, guided by study findings, researchers could also create interventions to assess and increase knowledge of post-fall decision making among older adults. For example, a decision aid could be developed to help older women understand the risks of taking specific decisions after a fall. This decision aid could then be evaluated to increase knowledge and awareness of post-fall decision making (Schonberg, et al., 2014).

Study Strengths

I used mixed methods to explore decision making after a fall among older women residing in CCRCs (Patton, 2002). In the qualitative phase of this study, I thoroughly explored the experiences of older women after a fall and the decisions they made after such incidents. I used a community-driven approach to recruit the second set of interviewees by asking women to identify the secondary informants themselves. The combination of the two sets of interviews (i.e., with the primary and secondary informants) provided a greater understanding of the process by which women make decisions alone or with others after a fall.

These qualitative results helped me develop the exploratory survey which I then administered to a broader range of older women, living in both CCRCs and non-institutional homes across the state of South Carolina. The survey results revealed that older women made an extensive amount of decisions after their falls. In addition, while decisional conflict exists in post-fall decision making, several options can help decrease this uncertainty and facilitate informed decision making.

These results can now be shared with multiple audiences including older women who have fallen, professionals working with older adults, family members involved in the post-fall decision-making process, extended family, falls prevention practitioners, policy makers, as well as in different settings including CCRCs, senior centers, and in falls prevention interventions. The ultimate goal of communicating the results of this study is to help older women with their post-fall decision-making processes so they can quickly and successfully regain their health, independence, and quality of life after a fall.

Limitations

Several factors limit the generalizability and/or transferability of the results. First, I relied on participant self-report for primary data collection. I trusted that participants were honest in both the interviews and the surveys, but it is impossible for me to examine the accuracy of their post-fall experiences by comparing their responses to other sources of data.

All of the primary informants for the interviews were White educated women living in CCRCs. The qualitative results of this study may therefore not be generalizable to women of different races, those of lower education levels, and those living in other settings. Similarly for the survey, although I recruited White and African American participants, from CCRCs and non-institutional homes, I only recruited participants in the

state of South Carolina. Results may therefore not apply to older women living in other states or countries, and may possibly not reflect the experiences of older men (Creswell, 2009; Patton, 2002).

For the exploratory survey, I had a sample of 130 older women who reported adequate health literacy, i.e., only 11 out of 130 women reported having low health literacy. This lack of variance in health literacy prevented me from assessing the moderating effect of health literacy on the relationship between post-fall decision category and decisional conflict. I used a cross-sectional design which did not allow me to claim causality between variables (Shadish, Cook, & Campbell, 2002). Nonetheless, these few limitations do not diminish the value and importance of this study on post-fall decision making among older women.

Conclusions

Other than limited studies on coping strategies after a fall (e.g., Host et al., 2011; Roe et al., 2008), and other studies on the emotional responses after a fall (e.g. Calhoun et al., 2011), this mixed-methods dissertation was one of the first studies to (1) focus on older women residing in CCRCs, and (2) explore decision making after a fall. Although I primarily focused on the experiences and decisions of independent older women residing in CCRCs, I also included older women living in non-institutional homes in phase 2 of the research to make the results more applicable and relevant to a broader population of older adults. This study showed how important it is to understand the post-fall decision-making process, including what decisions older women make after experiencing a fall, how they make these decisions, and what factors influence the decision-making process, in order to help older women manage their fall experiences and

regain their strength and quality of life. It is crucial that all those involved in the health of older women become educated about post-fall decision making so that together they can help manage and prevent falls that cause significant morbidity and mortality in the older population.

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APPENDIX A
RECRUITMENT FLYER FOR
INTERVIEWS WITH PRIMARY INFORMANTS

HAVE YOU EXPERIENCED A FALL
WITHIN THE LAST SIX MONTHS?

Would you like to talk about your experience and
contribute to research in aging?

SEEKING WOMEN AGED 65+
LIVING IN A CONTINUING
CARE RETIREMENT
COMMUNITY (CCRC) IN THE
COLUMBIA AREA FOR AN
INTERVIEW ABOUT
POST-FALL EXPERIENCES.



Participate in 1 one-on-one interview and complete 1 brief survey.

The interview will last a total of 1.5 hours.

Each participant will receive **\$30** for her time.

To sign up, please call Caroline Bergeron, MSc, doctoral candidate
and student researcher at 803-629-8635.

This study has been approved by the Institutional Review Board
at the University of South Carolina. The study is funded by the
Canadian Institutes of Health Research.



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APPENDIX B

INTERVIEW GUIDE FOR PRIMARY INFORMANTS



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Post-Fall Decision Making among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

Student Researcher: Caroline D. Bergeron, MSc, DrPH(c)

Faculty Supervisor: Daniela B. Friedman, MSc, PhD

Department of Health Promotion, Education, and Behavior

Purpose

Thank you for taking the time to participate in this interview. These interviews will be used as part of my doctoral dissertation regarding falls among older adults. The purpose of this interview is to better understand how decisions are made after someone experiences a fall. The information gathered from these interviews will help you and other people prevent falls. I won't share anything you tell me today with your relatives and staff at [CCRC]. All the information you tell me will remain strictly confidential and anonymous. Please try to tell me as much as you can and remember. I'm not judging you. I just want you to be very honest ok? It's by being honest and sharing as much as you can about your experiences that I will gather real information that can help other people prevent and manage falls. Is that okay? Also if there is anything you do not understand, just let me know so I can rephrase it or repeat it, if you need me to. This interview should last about an hour.

Introduction

- In the past 6 months (since the month of [add month here]), how many times have you fallen?
 - If one fall: Let's talk about this fall. (Go to next section.)
 - If more than one fall: Thinking about these various falls, is there one of these falls that you consider the "most significant"?
 - If yes, go to next section.
 - If no, ask participant to talk about their most recent fall, as they may remember it best.

Background on the most significant/recent fall

As I ask you questions, I want you to think about this most significant/recent fall. First I will ask you some general questions about this most significant/recent fall.

- Tell me about this fall.
 - What happened?
 - When did you fall?
 - Where did you fall?
 - How did you fall?
 - What do you think caused you to fall?
 - What kind of help, if any, did you receive immediately after your fall?
 - Who knows about this fall? How did they find out?
 - What happened after you fell?
 - What were the consequences of this fall? (probes: bruises, knee injury, broken hip)
- How did you feel after this fall?
 - Describe the emotions you felt at the time/after the fall.
- For a woman like you, living in a CCRC like [name of facility], what are some of the possible short-term and long-term "consequences" of falling?
 - How do you feel about these possibilities?

Decisions and changes

Now I'd like you to talk more specifically about the decisions you may have taken after this fall and the changes you made as a result of these decisions.

- Thinking about this fall you just described, what type of decisions did you make after your fall regarding your health?
 - What, if anything, did you do differently in your daily activities? (probe: get assistance with chores; exercise daily)
 - What, if any changes, did you make in your living arrangements? (probe: reduce clutter in apartment)
- What changes did you have to make in your life and/or environment to respond to these decisions? (probes: use a walker, remove carpets, go to rehab)
- Other than these changes, what else resulted from your post-fall decisions to [add decision here]? (probes: felt more secure, gained some strength)
- How did making these changes (i.e., using a walker, moving to another level of care, etc.) affect how you feel about falling?

Decision-making process

Thinking about the changes you made, the next set of questions is about how you made these decisions to [add the main decision mentioned] after this most significant/recent fall.

- What type of information, if any, did you seek in order to decide to [add decision mentioned]?
 - Where did you get that information? (probes: in the newspaper, on television)
 - What did you think of this information? (probes: useful, credible, trustworthy)
 - What information did you pay attention to or use in your decision making? Why?
 - What information did you discard or not use in your decision making? Why?

- Sometimes, others are also involved in the decision-making process after a fall. Thinking about [add decision mentioned], who, if anybody, helped you make this decision?
 - [Depending on how many people the participant names] Going one by one, who is he/she and/or how do you know him/her?
 - What is your relationship with him/her?
 - How often do you communicate?
 - How often did you talk after your fall?
 - What type of information did he/she give you after your fall?
 - What kind of help/advice did he/she give you?
 - What did you do with this advice? (probes: discard it, consider it, follow it)

- Among all these contacts, who would you say provided you with the best advice? Why?

- Among all these contacts, which ones would you say are credible sources of information? Why?

- Among these people, which ones did you trust the most? Why?
- Thinking about all the people that helped you after your fall, how did these people influence your decision?
 - Did you feel any pressure about making this particular decision? By whom?

- Thinking again about all the people who helped you and all the information you received and found by yourself, how do you feel about this decision and the changes you have made to your life?

- Looking back at your experience of having fallen, and the decisions and changes you made as a result, what kind of advice would you give to another resident of [add name of CCRC] who experienced a fall like you did?
 - What would you tell them specifically?
- If you were to have another fall, how do you anticipate your experience to be different or the same as what you just lived?
 - How would the decisions you make and/or changes in your life/environment be similar or different to the ones we discussed today regarding your previous fall?
- As part of this project, I am also speaking with people who helped make these post-fall decisions. Would you be comfortable with me getting in touch with one of your contacts for an interview?
 - Which three people do you think were the most involved in your decision-making process?
 - Can you please provide me with their contact information?

Conclusion

We've talked about your most significant/recent fall, the decisions and changes that you made, as well as sources of information that helped you make these decisions.

- Can you think of any other information that you would like to share that we haven't talked about?

Thank you so much for taking the time to talk with me about your experiences. I really appreciate your input.

APPENDIX C
INFORMATION LETTER AND CONSENT FORM FOR
INTERVIEWS WITH PRIMARY INFORMANTS



UNIVERSITY OF
SOUTH CAROLINA
Arnold School of Public Health



Post-Fall Decision Making among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

Student Researcher: Caroline D. Bergeron, MSc, DrPH(c)

Faculty Supervisor: Daniela B. Friedman, MSc, PhD

Department of Health Promotion, Education, and Behavior

Introduction and Purpose

You are invited to take part in a research study being conducted by Caroline Bergeron, a doctoral candidate in the Arnold School of Public Health at the University of South Carolina. You are being asked to participate in this research study because you are a woman, aged 65 and over, who speaks and reads English and is currently living in a continuing care retirement community, who has experienced a fall within the last six months and suffered at least a minor injury which caused you to limit your regular activities for at least one day. Caroline is conducting this research study to find out how older women make decisions after experiencing a fall. This study is funded by the Canadian Institutes of Health Research. This form explains what you will be asked to do if you decide to take part in this study. Please read it carefully and feel free to ask any questions before you make a choice about taking part in this study.

Description of Study Procedures

If you decide to take part in this study, you will be asked to take part in one 90 minute interview. The interview will be audio-recorded. You will also be asked to complete a brief demographic survey at the end of the interview. During the interview, you will be asked about (1) the meaning of your fall, (2) the decisions and changes you made after your fall, and (3) who or what may have helped you make these post-fall decisions. All study activities will take place at a mutually agreed upon time and place.

Risks of Participation

There are no known risks associated with taking part in this research. However, there is a small chance that you may feel uncomfortable sharing some personal stories regarding your most significant/recent fall. Overall, you should not suffer any physical or emotional outcome from participating in this study. You do not have to answer any questions that you do not wish to answer and are free to stop the interview at any time. Lastly, there is a minimal risk that anonymity can be breached through study records or audio-recordings, but we will do everything possible to keep your information protected.

Benefits of Participation

You may benefit directly from taking part in this study by reflecting and getting insight into your own post-fall experiences, as well as by learning about different options available in long-term care. You may also benefit others by sharing your experiences and helping us increase awareness and attention of post-fall decision making among older women.

Costs

There will be no costs to you for taking part in this study (other than for your time).

Payments

You will receive **\$30 in cash** for taking part in this interview and for completing a brief survey.

Anonymity of Records

The information that you provide us with during this study will be kept private as much as possible. A number (code) will be assigned to you at the beginning of the study. This number will be used on study records rather than your name, and no one other than the student researcher and her dissertation chair will be able to link your information with your name. All names and other personal identifying information **will not** be included in the transcript and the audio-recordings will be destroyed following transcription. All information will be kept anonymous. The results of the study may be published or presented at professional meetings, but your identity will not be shared. All study records/data including the transcripts, the demographic surveys, the audio files, and the consent forms will be stored in locked filing cabinets and protected computer files at the University of South Carolina.

Caroline, the student researcher conducting this study, as well as her dissertation chair, will be the only ones to have access to identifiable information. In rare cases, a research study may be evaluated by an oversight agency, such as the USC Institutional Review Board. If this occurs, records that identify you and the consent form signed by you may

be looked at so that they may decide whether the study was properly carried out and your rights of participants were protected.

Contact Persons

For more information about this research, please contact Caroline Bergeron (student researcher) at (803) 629-8635 or bergeroc@email.sc.edu or Dr. Daniela B. Friedman (faculty supervisor) at (803) 576-5641 or dbfriedman@sc.edu. If you have any questions about your rights as a research participant, please contact, Lisa Marie Johnson, Institutional Review Board Manager, Office of Research Compliance, University of South Carolina, Columbia, SC 29208 at (803) 777-6670 or lisaj@mailbox.sc.edu.

Voluntary Participation

The choice to take part in this study **or not** is yours. You are free not to take part or to quit taking part in this study at any time, for whatever reason, without negative consequences. In the event that you quit this study, the information you have already given us will be kept private.

Signatures /Dates

I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to take part in this study, although I have been told that I may quit at any time without negative consequences. I have been given (or will be given) a copy of this form for my records and future reference.

Name (please print): _____

Signature: _____

Date: _____

Witness: _____

I also agree to be contacted by the student researcher to verify the information collected during this interview.

Yes, it is okay to contact me in the future.

No, it is not okay to contact me in the future.

Telephone number: _____

APPENDIX D
DEMOGRAPHIC SURVEY FOR PRIMARY INFORMANTS



Post-Fall Decision Making among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

Student Researcher: Caroline D. Bergeron, MSc, DrPH(c)

Faculty Supervisor: Daniela B. Friedman, MSc, PhD

Department of Health Promotion, Education, and Behavior

These few questions will help us understand more about who you are. Please mark your answer clearly by placing a check mark (☑) in the box next to your response. Note that all answers will be kept anonymous.

1. What year were you born? _____

2. Which of the following races best describes you?

White, not Hispanic..... []

Black, not Hispanic..... []

Hispanic/Latino..... []

Other..... []

3. What is your current marital status?

Single/Never married..... []

Married/Living with partner.... []

- Separated..... []
- Divorced..... []
- Widowed..... []
- Other..... []

4. What is the highest level of education you have completed?

- Less than high school..... []
- High school degree or GED..... []
- Some college..... []
- Bachelor's degree..... []
- Advanced/graduate degree..... []

5. What is your current living situation?

- Living alone..... []
- Living with spouse/partner..... []
- Other..... []

6. Since when (month and year) have you been living in this continuing care retirement community? _____

7. When was your most significant/recent fall (approximate month and date)

(e.g., October 8)? _____

8. What body part did you hurt or injure in your most significant/recent fall?

(Check all that apply.)

Back.....

Hip.....

Knee.....

Leg.....

Arm.....

Wrist.....

Ankle.....

Head.....

Not applicable.....

Other.....

Please specify: _____

9. Who or what helped you make decisions after your fall? (Check all that apply.)

Husband/Partner.....

Daughter.....

Son.....

Grandchild.....

Other relative.....

Friend.....

Neighbor.....

Physician.....

CCRC staff..... []

Media (e.g., TV, radio, newspapers, internet).. []

Other..... []

Please specify: _____

10. How many falls have you had in the last six months?

One fall..... []

Two to three falls..... []

Four to five falls..... []

Six to ten falls..... []

More than ten falls..... []

Thank you for your participation.

APPENDIX E INTERVIEW GUIDE FOR SECONDARY INFORMANTS



UNIVERSITY OF
SOUTH CAROLINA
Arnold School of Public Health



Post-Fall Decision Making among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

Student Researcher: Caroline D. Bergeron, MSc, DrPH(c)

Faculty Supervisor: Daniela B. Friedman, MSc, PhD

Department of Health Promotion, Education, and Behavior

Introduction/Purpose

Thank you for taking the time to participate in this interview. These interviews will be used as part of my doctoral dissertation regarding falls among older adults. The purpose of this interview is to better understand how decisions are made after someone experiences a fall. You were identified by [CCRC Resident's Name] as someone who is familiar with a fall that she had within the previous six months. Your feedback today will be invaluable in understanding how these post-fall decisions can sometimes be made collectively with an older adult and other individuals. It may also help with future falls prevention initiatives. The information you tell me today will remain anonymous. This interview should last approximately 60 minutes.

Background on relationship to participant

To start, I will ask you some general questions about your relationship with [CCRC Resident's Name].

- What is your relation to [CCRC Resident's Name]?
- What kind of relationship do you have?
 - How often do you communicate with [CCRC Resident's Name]?

Background on her most significant/recent fall

- When I talked with [CCRC Resident's Name], we talked about the time she fell [give details such as day, time]. For the purpose of this research, we are calling this a "significant/most recent" fall that recently occurred in her life. Please tell me what you know about this fall.

- Where did she fall?
- How did she fall?
- What do you think caused her fall?
- What kind of help did she receive immediately after her fall?
- Who do you think knows about her fall?
- What were the consequences of this fall? (probes: bruises, knee injury, broken hip)
- Why do you think this fall was significant for her? (probes: her only fall, because of the injury)
- What are some of the changes she made, if any, after her fall? (probes: use a walker, remove carpets)
- How did she decide to make these changes?

Involvement in decisions

The next set of questions relates to your involvement in her post-fall decisions.

- How were you involved in the decisions that she made after her fall?
 - Did she ask you for information or advice? Why do you think that is?
- What type of information or advice, if any, did you provide her after her fall?
 - Why did you provide this information?
 - How often would you say you mentioned these suggestions to her after her fall?
- How did [CCRC Resident's Name] respond to the information or advice you gave her?
 - Why do you think that is?
- To your knowledge, what type of information did she also receive from other people or other sources? (probes: CCRC staff, media)
- In your opinion, how important was your feedback in her decision-making process?
 - Why do you think that is?
- What was [CCRC Resident's Name]'s final decision?
 - What do you think about the changes [CCRC Resident's Name] decided to make?
 - How do you feel about it? (probes: unsatisfied, fine)
- If you had any recommendations to make to women who experience a fall, what would you tell them?

- If you had any recommendations for people like you who are involved in this decision-making process, what would you tell them?

Conclusion

We've talked about your relationship with [CCRC Resident's Name], the decisions that she made after her fall, and your role in these decisions. Can you think of any other information that you would like to share that we haven't talked about?

Thank you so much for taking the time to talk with me about your experiences regarding [CCRC Resident's Name]'s post-fall decision making. I really appreciate your input. Please thank [CCRC Resident's Name] for putting us in contact.

APPENDIX F
INFORMATION LETTER AND CONSENT FORM FOR INTERVIEWS
WITH SECONDARY INFORMANTS



UNIVERSITY OF
SOUTH CAROLINA
Arnold School of Public Health



Post-Fall Decision Making among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

Student Researcher: Caroline D. Bergeron, MSc, DrPH(c)

Faculty Supervisor: Daniela B. Friedman, MSc, PhD

Department of Health Promotion, Education, and Behavior

Introduction and Purpose

You are invited to take part in a research study being conducted by Caroline Bergeron, a doctoral candidate in the Arnold School of Public Health at the University of South Carolina. You are being asked to participate in this research study because you were named by one of our study participants as her main source of information after her fall. Caroline is conducting this research study to find out how older women make decisions after experiencing a fall as well as how the women's information sources contribute to her post-fall decision-making process. This study is funded by the Canadian Institutes of Health Research. This form explains what you will be asked to do if you decide to take part in this study. Please read it carefully and feel free to ask any questions before you make a choice about taking part in this study.

Description of Study Procedures

If you decide to take part in this study, you will be asked to take part in one 60 minute interview. The interview will be audio-recorded. You will also be asked to complete a brief demographic survey at the end of the interview. During the interview, you will be asked about (1) the participant's most significant/recent fall, (2) the type of information and advice you shared with her, as well as (3) how you viewed your role in her decision-making process. All study activities will take place at a mutually agreed upon time and place.

Risks of Participation

There are no known risks associated with taking part in this research. However, there is a small chance that you may feel uncomfortable sharing some personal stories regarding

the participant's most significant/recent fall. Overall, you should not suffer any physical or emotional outcome from participating in this study. You do not have to answer any questions that you do not wish to answer and are free to stop the interview at any time. Lastly, there is a minimal risk that anonymity can be breached through study records or audio-recordings, but we will do everything possible to keep your information protected.

Benefits of Participation

You may benefit directly from taking part in this study by reflecting on your involvement in the study participant's decision-making process. You may also benefit others by sharing your experiences and involvement in this process and helping us increase awareness and attention of older women's post-fall decision making.

Costs

There will be no costs to you for taking part in this study (other than for any parking/gas expenses you may have and your time).

Payments

You will receive **\$30 in cash** for taking part in this interview and for completing a brief survey.

Anonymity of Records

The information that you share during this study will be kept private as much as possible. A number (code) will be assigned to you at the beginning of the study. This number will be used on study records rather than your name, and no one other than the researchers will be able to link your information with your name. All names and other personal identifying information **will not** be included in the transcript and the audio-recordings will be destroyed following transcription. All information will be kept anonymous. The results of the study may be published or presented at professional meetings, but your identity will not be shared. All study records/data including the transcripts, the demographic surveys, the audio files, and the consent forms will be stored in locked filing cabinets and protected computer files at the University of South Carolina.

Caroline, the student researcher conducting this study, as well as her dissertation chair, will be the only ones to have access to identifiable information. In rare cases, a research study may be evaluated by an oversight agency, such as the USC Institutional Review Board. If this occurs, records that identify you and the consent form signed by you may be looked at so that they may decide whether the study was properly carried out and your rights of participants were protected.

Contact Persons

For more information about this research, please contact Caroline Bergeron (student researcher) at (803) 629-8635 or bergeroc@email.sc.edu or Dr. Daniela B. Friedman (faculty supervisor) at (803) 576-5641 or dbfriedman@sc.edu. If you have any questions about your rights as a research participant, please contact, Lisa Marie Johnson, Institutional Review Board Manager, Office of Research Compliance, University of South Carolina, Columbia, SC 29208 at (803) 777-6670 or lisaj@mailbox.sc.edu.

Voluntary Participation

The choice to take part in this study **or not** is yours. You are free not to take part or to quit taking part in this study at any time, for whatever reason, without negative consequences. In the event that you quit this study, the information you have already given us will be kept private.

Signatures /Dates

I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to take part in this study, although I have been told that I may quit at any time without negative consequences. I have been given (or will be given) a copy of this form for my records and future reference.

Name (please print): _____

Signature: _____

Date: _____

Witness: _____

I also agree to be contacted by the student researcher to verify the information collected during this interview.

Yes, it is okay to contact me in the future.

No, it is not okay to contact me in the future.

Telephone number: _____

APPENDIX G
DEMOGRAPHIC SURVEY FOR SECONDARY INFORMANTS



Post-Fall Decision Making among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

Student Researcher: Caroline D. Bergeron, MSc, DrPH(c)

Faculty Supervisor: Daniela B. Friedman, MSc, PhD

Department of Health Promotion, Education, and Behavior

These few questions will help us understand more about who you are. Please mark your answer clearly by placing a check mark (☑) in the box next to your response. Note that all answers will be kept anonymous.

1. What year were you born? _____

2. Which of the following races best describes you?

White, not Hispanic..... []

Black, not Hispanic..... []

Hispanic/Latino..... []

Other..... []

3. What is your current marital status?

Single/Never married..... []

Married/Living with partner.... []

- Separated..... []
- Divorced..... []
- Widowed..... []
- Other..... []

4. What is the highest level of education you have completed?

- Less than high school..... []
- High school degree or GED..... []
- Some college..... []
- Bachelor's degree..... []
- Advanced/graduate degree..... []

5. What is your annual household income (before taxes)?

- Less than \$20,000..... []
- \$20,000 to \$39,999..... []
- \$40,000 to \$59,999..... []
- \$60,000 to \$79,999..... []
- \$80,000 to \$99,999..... []
- Over \$100,000..... []

6. What is your relation to the participant? You are primarily her...

- Husband/Partner..... []
- Daughter..... []

- Son.....
- Grandchild.....
- Other relative.....
- Friend.....
- Neighbor.....
- Physician.....
- CCRC staff.....
- Other.....
- Please specify: _____

7. How frequently do you communicate with the participant?

- Multiple times a day.....
- Once a day.....
- A few times a week.....
- Once a week.....
- A few times a month.....
- Once a month.....
- Once every two months.....
- A few times a year.....
- Other.....
- Please specify: _____

8. How involved were you in the participant's post-fall decision making?

Not at all involved..... []

Somewhat involved..... []

Involved..... []

Very involved..... []

9. How important do you think was your involvement in the participant's post-fall decision making?

Not at all important..... []

Somewhat important..... []

Important..... []

Very important..... []

Thank you for your participation.

APPENDIX H
RECRUITMENT FLYER FOR SURVEYS WITH
PRIMARY INFORMANTS LIVING IN CCRCs

HAVE YOU EXPERIENCED A FALL
WITHIN THE LAST YEAR?



SEEKING WOMEN AGED 65+
LIVING INDEPENDENTLY IN
A CONTINUING CARE
RETIREMENT COMMUNITY
(CCRC) IN SOUTH CAROLINA
TO COMPLETE A SURVEY
ABOUT THEIR DECISIONS
AFTER A FALL.

Participate in 1 survey about your decisions after a fall.

The survey will take about 20 minutes to complete.

Each survey participant will receive **\$15** for her time.

To sign up, please call Caroline Bergeron, MSc, doctoral candidate
and student researcher at 803-629-8635.

This study has been approved by the Institutional Review
Board at the University of South Carolina. This study is funded
by the Canadian Institutes of Health Research.



UNIVERSITY OF
SOUTH CAROLINA
Arnold School of Public Health



APPENDIX I
RECRUITMENT FLYER FOR SURVEYS WITH PRIMARY INFORMANTS
LIVING IN NON-INSTITUTIONAL HOMES

HAVE YOU EXPERIENCED A FALL
WITHIN THE LAST YEAR?



SEEKING WOMEN AGED
65+ LIVING
INDEPENDENTLY IN SOUTH
CAROLINA TO COMPLETE A
SURVEY ABOUT THEIR
DECISIONS AFTER A FALL.

Participate in 1 survey about your decisions after a fall.

The survey will take about 20 minutes to complete.

Each survey participant will receive **\$15** for her time.

To sign up, please call Caroline Bergeron, MSc, doctoral candidate
and student researcher at 803-629-8635.

This study has been approved by the Institutional Review
Board at the University of South Carolina. This study is funded
by the Canadian Institutes of Health Research.



UNIVERSITY OF
SOUTH CAROLINA
Arnold School of Public Health



HAVE YOU EXPERIENCED A FALL WITHIN THE LAST YEAR?



SEEKING WOMEN AGED
65+ LIVING
INDEPENDENTLY IN SOUTH
CAROLINA TO COMPLETE A
SURVEY ABOUT THEIR
DECISIONS AFTER A FALL.

Participate in 1 survey about your decisions after a fall.

The survey will take about 20 minutes to complete.

Each survey participant will receive **\$15** for her time.

To sign up, please call Caroline Bergeron, MSc, doctoral candidate
and student researcher at 803-629-8635.

This study has been approved by the Institutional Review
Board at the University of South Carolina. The study is funded
by the Canadian Institutes of Health Research.



UNIVERSITY OF
SOUTH CAROLINA
Arnold School of Public Health



APPENDIX J
EXPLORATORY SURVEY FOR PRIMARY INFORMANTS



UNIVERSITY OF
SOUTH CAROLINA
Arnold School of Public Health



Post-Fall Decision Making among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

Student Researcher: Caroline D. Bergeron, MSc, DrPH(c)

Faculty Supervisor: Daniela B. Friedman, MSc, PhD

Department of Health Promotion, Education, and Behavior

Introduction

You are being asked to complete this survey because you are a woman aged 65 or older who currently lives independently in South Carolina. You have also experienced a fall in the past year that resulted in at least a minor injury which caused you to limit your regular activities for at least one day. Caroline Bergeron, a doctoral student in the Arnold School of Public Health at the University of South Carolina, is conducting this study as part of her dissertation research to find what factors may have affected the decisions you made after your fall. Your answers will be kept anonymous. The survey will take approximately 20 minutes to complete and you will receive \$15 for your time. Please communicate with Caroline in person, by telephone at 803-629-8635, or by email at bergeroc@email.sc.edu if you have any questions or concerns. Thank you for your help with this important project!

Please mark your answer clearly by placing a check mark (☑) in the box next to your response. Note that all answer will be kept anonymous.

Section A: The first questions are about your health.

A1. In general, would you rate your health as:

- | | |
|----------------|-----|
| Excellent..... | [] |
| Very good..... | [] |
| Good..... | [] |
| Fair..... | [] |
| Poor..... | [] |

A2. How often do you have someone help you read instructions, pamphlets, or other written material from your doctor or pharmacy?

- | | |
|----------------|-----|
| Never..... | [] |
| Rarely..... | [] |
| Sometimes..... | [] |
| Often..... | [] |
| Always..... | [] |

Section B: The next questions are about your experiences with falls. Please mark your answer clearly by placing a check mark (☑) in the box next to your response.

B.1. How often have you fallen in the past year?

- Once.....
- A few times in the year.....
- Once every couple of months.....
- Once a month.....
- A few times a month, but not every week.....
- Every week.....

B.2. Considering all of your falls in the past year, how severe were your fall(s)?

- Very minor.....
- Minor.....
- Moderate.....
- Severe.....
- Very severe.....

Section C: The next questions are about the changes you made after experiencing a fall.

C.1. Which changes did you make after experiencing a fall? Place a check mark (☑) in the box next to your answer only if you made the change listed.

	<i>Yes, I made this change.</i>
a. Go see a doctor?	[]
b. Go to a rehabilitation facility?	[]
c. Go to physical therapy?	[]
d. Exercise outside of your home?	[]
e. Do exercises at home (e.g., in your apartment)?	[]
f. Take pain medication?	[]
g. Get more rest?	[]
h. Drink less alcohol?	[]
i. Drink more water?	[]

Which changes did you make after experiencing a fall? Place a check mark (☑) in the box next to your answer only if you made the change listed.

	<i>Yes, I made this change.</i>
j. Have a therapist come into your home to make suggestions about how to reduce your risks of falling?	[]
k. Remove carpets or rugs?	[]
l. Install handrails?	[]
m. Install bed rails?	[]
n. Use a night light?	[]
o. Get new shoes?	[]

C.1. (continued) Which changes did you make after experiencing a fall? Place a check mark (☑) in the box next to your answer only if you made the change listed.

	<i>Yes, I made this change.</i>
p. Get help from others (e.g. in the shower, for transportation)?	[]
q. Get help from God (e.g. through prayer)?	[]
r. Wear an emergency pendant, button, or life alert?	[]
s. Use a walker?	[]
t. Use a cane?	[]
u. Use a wheelchair?	[]
v. Get a lift chair?	[]
w. Use hand grip reachers?	[]
x. Use a shower seat?	[]
y. Use pull chords?	[]

Which changes did you make after experiencing a fall? Place a check mark (☑) in the box next to your answer only if you made the change listed.

	<i>Yes, I made this change.</i>
z. Slow down?	[]
aa. Be careful when walking?	[]
bb. Take more breaks when walking?	[]
cc. Pick up feet when walking?	[]
dd. Look where you are walking?	[]
ee. Hold on when walking (e.g., hold on to furniture, to people, to wall)?	[]

C.1. (continued) Which changes did you make after experiencing a fall? Place a check mark (☑) in the box next to your answer only if you made the change listed.

	<i>Yes, I made this change.</i>
ff. Avoid going certain places where you might fall?	[]
gg. Avoid telling people about your fall?	[]
hh. Avoid getting help from others?	[]
ii. Other? Specify: _____ _____	[]

C.2. From the list in the previous three pages (Question C1), please write below your three most important changes.

e.g., Your most important change: Get a life alert pendant

1- Your most important change:

2- Your second most important change:

3- Your third most important change:

Section D: The next section is based on the change that you ranked the most important change after your fall in the last section.

D.1 Write your most important change after your fall here again on the lines below:

D.2. The following questions are about this specific change. In reference to this specific change, please indicate how much you agree or disagree with the following statements. Answer each question by using a scale from 1 to 5, where 1 = “I strongly disagree” and 5 = “I strongly agree”. Please mark your answer clearly by placing a check mark (☑) in the box next to your response.

	<i>I strongly disagree</i> 1	<i>I disagree</i> 2	<i>I neither disagree nor agree</i> 3	<i>I agree</i> 4	<i>I strongly agree</i> 5
a. The decision to make this change was easy for me to make.	[]	[]	[]	[]	[]
b. I felt I needed more advice and information before making this decision.	[]	[]	[]	[]	[]
c. I felt pressure from others in making this decision.	[]	[]	[]	[]	[]
d. I had the right amount of support from others in making this decision.	[]	[]	[]	[]	[]
e. I feel I have made an informed choice.	[]	[]	[]	[]	[]

f. The decision I made to make this change was the best decision possible for me personally.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. My decision shows what is most important for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I expect to stick with this decision and change.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I am satisfied with my decision to make this change.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section E: The next set of questions is about health and support services to help meet specific needs over an extended period of time.

E1. Read each statement below and indicate how familiar you are with each of the care options presented. Answer each question by using a scale from 1 to 5, where 1 = “I am not at all familiar” and 5 = “I am very familiar.” Please mark your answer clearly by placing a check mark (☑) in the box next to your response.

	<i>I am not at all familiar</i>	<i>I am not familiar</i>	<i>I am neither not familiar nor familiar</i>	<i>I am familiar</i>	<i>I am very familiar</i>
	1	2	3	4	5
a. Adult day care? <u>Definition:</u> Structured programs that provide social and support services during <u>part</u> of a day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Assisted living? <u>Definition:</u> Residence that provides individualized personal care and assistance with activities like bathing, dressing, and eating, help with medication, and other services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Nursing home? <u>Definition:</u> Licensed facility that provides general nursing care to those who are unable to take care of daily living needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

E.2. Please think about the fall(s) that you experienced in the past year. Indicate how open you would be to accepting the following care options if you needed assistance after your fall(s). Answer each question by using a scale from 1 to 3, where 1 = “I am not at all open” and 3 = “I am open.” Please mark your answer clearly by placing a check mark (☑) in the box next to your response.

	<i>I am not at all open</i> 1	<i>I am somewhat open</i> 2	<i>I am open</i> 3
a. Adult day care? <u>Definition:</u> Structured, comprehensive programs that provide social and support services during part of a day.	[]	[]	[]
b. Assisted living? <u>Definition:</u> Residential facility that provides individualized personal care, assistance with activities of daily living, help with medication, and other services.	[]	[]	[]
c. Nursing home? <u>Definition:</u> Licensed facility that provides general nursing care to those who are unable to take care of daily living needs.	[]	[]	[]

Section F. The last questions are about YOU. Please mark your answer clearly by writing your answer or placing a check mark (☑) in the box next to your response.

F.1. What is your year of birth? _____

F.2. Which of the following best describe your racial/ethnic background?

- White, not Hispanic..... []
- Black, not Hispanic..... []
- Hispanic/Latino..... []
- Asian..... []
- Native American..... []
- Other..... []

F.3. What is your current marital status?

- Single/Never married..... []
- Married/Living with partner..... []
- Separated..... []
- Divorced..... []
- Widowed..... []
- Other..... []

F.4. What is the highest level of education you have completed?

- Less than high school..... []
- Some high school..... []
- High school degree/GED..... []
- Some college..... []
- Bachelor's degree..... []
- Advanced/graduate degree..... []

F.5. What is your current living situation?

- Living alone..... []

Living with spouse/partner..... []
Other..... []

F.6. Do you live in a retirement community?

No..... [] **Skip to F8.**
Yes..... [] **Go to F7.**

F.7. If so, how long have you been living in this retirement community?

F.8. Before today, were you interviewed by Ms. Bergeron about your previous falls?

No..... []
Yes..... []

F9. How did you hear about this study?

Presentation at the retirement community..... []
Staff at the retirement community..... []
Resident at the retirement community..... []
Family member..... []
Friend..... []
Flyer..... []
Radio advertisement..... []
Other..... []
Specify: _____

Thank you for your participation!

APPENDIX K
INFORMATION LETTER AND CONSENT FORM FOR SURVEY
WITH PRIMARY INFORMANTS



UNIVERSITY OF
SOUTH CAROLINA
Arnold School of Public Health



Post-Fall Decision Making among Older Women Living in Continuing Care Retirement Communities: A Mixed Methods Study

Student Researcher: Caroline D. Bergeron, MSc, DrPH(c)

Faculty Supervisor: Daniela B. Friedman, MSc, PhD

Department of Health Promotion, Education, and Behavior

Introduction and Purpose

You are invited to take part in a research study being conducted by Caroline Bergeron, a doctoral candidate in the Arnold School of Public Health at the University of South Carolina. You are being asked to complete this survey because you are a woman aged 65 or older who currently lives independently in South Carolina. You have also experienced a fall in the past year that resulted in at least a minor injury which caused you to limit your regular activities for at least one day. You are not eligible for this study if you have a visual impairment which prevents you from being able to read.

Caroline Bergeron, a doctoral student in the Arnold School of Public Health at the University of South Carolina, is conducting this study as part of her dissertation research to find what factors may have affected the decisions you made after your fall. This study is funded by the Canadian Institutes of Health Research. This form explains what you will be asked to do if you decide to take part in this study. Please read it carefully and feel free to ask any questions before you make a choice about taking part in this study.

Description of Study Procedures

If you decide to take part in this study, you will be asked to take part in one in-person, paper-pencil exploratory survey which will take approximately 20 minutes to complete. In the survey, you will be asked about (1) individual factors that may have influenced your decisions after your fall, such as your self-rated health and your familiarity with care options, (2) the types of changes you made after your

fall, and (3) how you felt about the decision to make those changes. All study activities will take place at a mutually agreed upon time and place.

Risks of Participation

There are no known risks associated with taking part in this research. However, there is a small chance that you may feel uncomfortable answering some of the questions regarding the frequency of your fall and how you felt about your decisions. Overall, you should not suffer any physical or emotional outcome from participating in this study. You do not have to answer any questions that you do not wish to answer and are free to stop the survey at any time. Lastly, there is a minimal risk that anonymity can be breached through study records, but we will do everything possible to keep your information protected.

Benefits of Participation

You may benefit directly from taking part in this study by reflecting and getting insight into your own post-fall experience and the individual factors that may have influenced your decision making. You may also benefit others by completing the survey and helping us increase awareness and attention of post-fall decision making among older women.

Costs

There will be no costs to you for taking part in this study (other than for your time).

Payments

You will receive **\$15 in cash** for taking part in the survey.

Anonymity of Records

The information that you provide us with during this study will be kept private as much as possible. A number (code) will be assigned to you at the beginning of the study. This number will be used on study records rather than your name, and no one other than the researchers will be able to link your information with your name. All names and other personal identifying information **will not** be included on the survey. All personal information will be kept anonymous. The results of the study may be published or presented at professional meetings, but your identity will not be shared. All study records/data including the surveys and the consent forms will be stored in locked filing cabinets and protected computer files at the University of South Carolina.

Caroline, the student researcher conducting this study, as well as her dissertation chair, will be the only ones to have access to identifiable information. In rare cases, a research study may be evaluated by an oversight agency, such as the USC Institutional Review Board. If this occurs, records that identify you and the consent form signed by you may

be looked at so that they may decide whether the study was properly carried out and your rights of participants were protected.

Contact Persons

For more information about this research, please contact Caroline Bergeron (student researcher) at (803) 629-8635 or by email at bergeroc@email.sc.edu, or Dr. Daniela B. Friedman (faculty supervisor) at (803) 576-5641 or dbfriedman@sc.edu. If you have any questions about your rights as a research participant, please contact, Lisa Marie Johnson, Institutional Review Board Manager, Office of Research Compliance, University of South Carolina, Columbia, SC 29208 at (803) 777-6670 or lisaj@mailbox.sc.edu.

Voluntary Participation

The choice to take part in this study **or not** is yours. You are free not to take part or to quit taking part in this study at any time, for whatever reason, without negative consequences. In the event that you quit this study, the information you have already given us will be kept private.

Signatures /Dates

I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to take part in this study, although I have been told that I may quit at any time without negative consequences. I have been given (or will be given) a copy of this form for my records and future reference.

Name (please print): _____

Signature: _____

Date: _____

Witness: _____