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Developing and Validating a Behavioral Framework for Dementia Care Partners' Fall  
Risk Management

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A dissertation  
submitted in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

University of Washington

2021

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School of Social Work

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**Abstract**

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Older adults living with dementia (OLWD) experience nearly two to ten times higher fall risk than older adults without dementia. Despite this, evidence is limited concerning effective fall management strategies for them. Care partners (broadly defined as relatives, partners, and friends) play a critical role in managing the fall risk for community-dwelling OLWD. However, it is unclear what behaviors dementia care partners adopt are relevant to fall risk management (FRM) and how these behaviors are associated with fall-related outcomes for OLWD. This dissertation utilizes an exploratory sequential mixed method study design to develop and validate a behavioral framework for dementia care partners' FRM.

This first paper proposes a behavioral framework for dementia care partners' FRM using a grounded theory approach and semi-structured, in-depth interviews with

14 care partners of community-dwelling OLWD. This paper makes a distinctive contribution by identifying eight domains of dementia care partners' FRM behaviors (1. functional mobility assistance, 2. assessing and addressing health conditions, 3. health promotions support, 4. safety supervision, 5. physical environment modification, 6. receiving, seeking, and coordinating care, 7. learning, and 8. self-adjustment) across four stages of FRM (1. providing support before dementia diagnosis, 2. preventing falls, 3. preparing to respond to falls, and 4. responding to falls).

The second paper validates this behavioral framework by using two linked national surveys, the National Health and Aging Trends Study (NHATS) 2015 and the National Study of Caregiving (NSOC) 2015, to examine the prevalence and dimensionality of care partners' FRM and to compare the differences between primary and secondary care partners. The exploratory factor analysis (EFA) approach under the item response theory paradigm is utilized to examine the dimensionality of FRM behaviors. EFA results illustrate the complexity of two domains of FRM behaviors that emerge from the first paper: receiving, seeking, and coordinating care, and assessing and addressing health conditions. These discrepancies illustrate the need to explore different mechanisms, facilitators, and barriers for care partners navigating multiple care systems and service providers and addressing different types of health conditions for managing OLWD's fall risk. Furthermore, this study identifies similarities and differences between primary and secondary care partners that may inform the development of different strategies to engage care partners based on their caring roles.

Informed by this validated framework, the third paper focuses on assessing fall risk reduction for community-dwelling OLWD associated with receipt of FRM support from their care partners utilizing longitudinal data NHATS 2015-2016 and the linked

care partner data NSOC 2015. Study findings from this paper highlight the importance of care partners' medication management, wound care, learning behaviors, accessing formal social care, and physical environment modifications in potentially reducing the risk of falling for community-dwelling OLWD. The study also found that certain FRM behaviors, including functional mobility assistance, health promotion support, and medication management might be associated with a higher risk of falling for OLWD.

Overall, the findings from this dissertation yield contribution to both practice and health and social behavior science inquiries. The dissertation addresses the need for a behavioral framework to understand care partners' FRM and assess the contributions and limitations of care partners' efforts. Future interventions can be developed by applying this framework to engage dementia care partners.

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## **ACKNOWLEDGMENTS**

This dissertation is the culmination of all my academic and professional journeys during my PhD study. I am very grateful for all the guidance, encouragement, hands-on training, and inspiration that I have received through my doctoral training.

First, I would like to thank my dissertation committee for their invaluable support and guidance since the first year of my PhD study. I feel extremely lucky to receive amazing mentorship from two Chairs, Dr. Nancy Hooyman (Year 1-3) and Dr. Clara Berridge (Year 4-5) to develop my program of research and to become an independent scholar. Their ongoing advice and encouragement allow me to explore my research interests, but also keep me focused on the direction that I am passionate about. I offer my thanks to Dr. Tatiana Sadak who was so generously taking me as a research practicum student since the first year of my PhD training and never stopped her support for my growth and learning. She has provided extensive training in dementia caregiving research and provided me many opportunities to participate in academic conference, publications, and introduce me to many mentors and collaborators. I also want to thank Dr. Elizabeth Phelan, who has been so devoted to support my interests in fall risk management and guided me to develop my expert in this field. Her encouragement and support allow me to continue this exciting adventure! I am also very thankful to Dr. Tracy Mroz and Dr. Janelle Taylor for their services as my Graduate School Representatives and their constant feedback to develop my dissertation.

I would like to offer my thanks for the following organizations for the funding and training support that I received for my advanced doctoral work: the National Association of Social Workers Foundation and the Council on Social Work Education

through Social Work Healthcare Education and Leadership Scholars (HEALS) Program; the Harry Bridges Center for Labor Studies, through the Martha H. Duggan Fellowship in Caring Labor; the University of Washington School of Social Work, through the Kath Wilham Doctoral Student Advanced Training Grant Award.

I would also want to thank my community partners. Through working with them, I was able to develop better understandings of the lived experiences of older adults living with dementia and their care partners. They also provided tremendous help for me to recruit participants for the dissertation, which meant so much to me.

I am very fortunate to be part of the social work community at the University of Washington. I have received wonderful mentoring from my first-year advisor Dr. Melissa Martinson, who had helped me with the critical transition when I just moved to Seattle from China. I have learned tremendously from Dr. Jane Lee when I was her research assistant. She has provided so many essential training and support to me in using mixed-method, doing health disparities research, and working with immigrant communities. She encouraged me to trust in myself and the work that I am doing! I am also received so much hands-on training from Dr. Rona Levy and Dr. David Takeuchi, when I was trying to develop my skills in grant writing in order to become an independent scholar. Thanks to my dear friends and colleagues Hazal Erçin, Sarah Jen, Ian Johnson, Alisa Strayer, Angela Fernandez, Erin Harrop, Claire Willey-Sthapit, Angie Malorni, Jessica Lapham, Youngjun Choi, Chiho Song, Asia Bishop, Matt Ignacio, Christopher Fleming, and Lan Thị Nguyễn, from whom I received incredible personal and intellectual support.

Finally, special thanks to my family in China and Mexico and to my beloved fiancé, Rodrigo Osuna-Orozco, who have always supported my passion in social work

research, gerontology, caregiving, and social justice. Without their support, none of these would be possible.

## **INTRODUCTION**

### **High Prevalence of Falls and Significant Negative Impact of Falls on Older Adults**

Falls are a significant public health problem that can hinder older adults' ability to age in place. The Centers for Disease Control and Prevention estimates that in 2014 approximately 29% of older adults (aged 65 or older) in the United States experienced a fall (Bergen, 2016). Falls are associated with major adverse consequences, including hospitalization, severe injuries such as hip fracture, residential care facility admission, and death (Peek et al., 2018). Therefore, the health care costs associated with falls are substantial (Burns et al., 2016; Davis et al., 2010; Finkelstein et al., 2005). Moreover, one-third of older people develop a fear of falling after an incidental fall, and those with a fear of falling have an increased risk of falling, compromised ability to perform activities of daily living, and lower quality of life (Masud & Morris, 2001).

### **Higher Risk of Falls and More Severe Impact of Falls on OLWD and Their Care Partners**

Epidemiologic research has found that for community-dwelling older adults, the incidence of falls in older adults living with dementia (OLWD) is about two to ten times higher than in those without dementia (Allan et al., 2009). OLWD are also more likely to be injured (Ek et al., 2018) and less likely to recover (B. R. Baker et al., 1978; Horgan et al., 1998), contributing to a higher rate of institutionalization (Morris et al., 1987) and mortality (B. R. Baker et al., 1978; N. L. Baker et al., 2011).

Falls in OLWD may also increase the care burden of their informal caregivers. One of the few studies of falls among persons living with dementia showed that fall incidents among people with the mild and moderate stages of Alzheimer's disease were

associated with caregiver burden (Kamiya et al., 2014). For people living with dementia, their prior month of falls represents a significant stressor that increases the odds that a caregiver will experience emotional difficulty even controlling for demographic characteristics and other primary and secondary stressors (Leggett et al., 2018).

### **Lack of Evidence in Fall Risk Management (FRM) for OLWD**

Despite the high risk of falls and negative impact of falls on OLWD and their caregivers, OLWD have largely been excluded from fall prevention intervention development (Booth et al., 2016; Faes et al., 2011), with the majority of inclusive fall prevention programs focused on exercise interventions (Miu et al., 2008; Öhman et al., 2016; Linda Teri et al., 2003; Yao et al., 2013). The evidence is limited concerning effective fall prevention strategies for community-dwelling OLWD (Peek et al., 2018). According to recent systematic reviews (Booth et al., 2016; Brims & Oliver, 2018; Burton et al., 2015, p. 2; Chan et al., 2015; Guo et al., 2014; Jensen & Padilla, 2017), only two studies demonstrated the effectiveness of exercise in reducing fall risk for OLWD (Pitkälä et al., 2013; Toulotte, 2003), and only one study reported that the use of home modification was significantly associated with a decreased risk of falling (Tchalla et al., 2013). Given the increasing prevalence of cognitive impairment caused by age-related neurodegeneration among the rapidly aging population worldwide, feasible and effective strategies to prevent falls among these older adults are needed.

### **Critical but Overlooked Roles of Dementia Care Partners**

Some researchers have suggested that informal care partners of OLWD might play important roles, either negative or positive, in managing falls for them (Buri &

Dawson, 2000; Meyer et al., 2019a; Padala et al., 2017; Taylor et al., 2017). Care partners, broadly defined as relatives, partners, and friends, often are responsible for managing the health of OLWD who live at home (Sadak et al., 2016). A previous study in the United States found that, for community-dwelling older adults living with cognitive impairment, high levels of informal care receipt ( $\geq 14$  informal care hours) were associated with a 54% risk reduction in fall-related injuries compared to those with no formal or informal care receipt (Hoffman et al., 2017). However, it is unknown which of the behaviors that informal care partners adopt result in fall risk reduction.

In earlier work, I conducted a systematic review that examined informal caregivers' (with the same definition of *informal care partner* in this dissertation) perceptual, emotional, and behavioral responses to fall risk in community-dwelling OLWD. This review identified the following care partners' multi-level efforts in FRM for OLWD:

- Individual level, including efforts such as keeping them company, increasing surveillance and restrictions, providing health promotion support, and communicating with them about fall risk (Malthouse & Fox, 2014; McIntyre & Reynolds, 2012; Peach et al., 2017; Wesson et al., 2013);
- Interpersonal level, defined as how they modified their own behaviors to adapt to the needs of fall management, such as changing their living arrangements and social lives due to OLWD's risk of falling (McIntyre & Reynolds, 2012);
- Physical environment level, referring to modifications of living environment (e.g., installing assistive technology and conducting home modifications) to manage the fall risk for OLWD (Allen et al., 2017; Chou et al., 2012);



- Community/institutional level, which include working with other informal/formal care systems, such as getting trained, linking OLWD with other care service resources through informal/formal care systems, and collaborating with professional health care team members (Forbes et al., 2013; Hattink et al., 2016; Öhman et al., 2016; Peach et al., 2017; Suominen et al., 2015; L. Teri et al., 1998).

Although this review revealed care partners' efforts in FRM, these findings need to be validated and expanded due to the limitations in the methodological quality of the reviewed studies: none of the studies systematically collected data on care partners' experiences in managing fall risk among OLWD. This review identified three major gaps:

- There is no behavioral framework to inform studies that explore dementia care partners' FRM.
- Few high-quality studies intentionally examine the impact of care partners' FRM behaviors on fall-related outcomes for OLWD.
- The factors that shape care partners' different behavioral responses to fall risk among OLWD are not identified.

These three gaps hinder our understanding of dementia care partners' roles in managing fall risk and how to engage care partners in future fall prevention interventions for OLWD. This dissertation aims to address the first two gaps to develop and validate a behavioral framework for dementia care partners' FRM. This framework will lay the conceptual and empirical foundation for future research to address the third gap, exploring the processes through which care partners develop their understanding

and strategies in managing fall risk in OLWD and identifying factors that shape their experiences.

### **Study Aims**

Building on my prior work, this dissertation aims to develop and validate a behavioral framework of dementia care partners' FRM and the impact of care partners' FRM behaviors on fall-related outcomes for OLWD. I first integrate four theoretical perspectives to inform the examination of dementia care partners' FRM, including (1) the multifactorial construct of fall risk among older adults (Casey et al., 2020; Katz, 2011; Rubenstein, 2006); (2) the construct of resilience process in dementia care partners (Zhou, Ishado, et al., 2020); (3) the theory of health behavior in an ecological context (Simons-Morton, 2013); and (4) previous empirical evidence of care partners' behavioral responses to fall risk among community-dwelling OLWD (Zhou, Strayer, et al., 2020). I then utilize these theoretical perspectives to inform an exploratory sequential mixed-method study with three specific aims for this three-paper dissertation: (1) to develop the behavioral framework of dementia care partner' FRM; (2) to validate the behavioral framework; and (3) to examine the associations between care partners' FRM behaviors and fall-related outcomes among community-dwelling OLWD.

The first paper, *Dementia care partners' fall risk management: Developing a behavioral framework using a grounded theory approach*, uses a qualitative study and a grounded theory approach through in-depth semi-structured interviews with 14 dementia care partners from Washington State. The findings propose a framework that

can be used to inform the development of multi-domain and multi-stage interventions and policy efforts to support care partners in FRM for community-dwelling OLWD.

The second paper, *Validation of a behavioral framework for dementia care partners' fall risk management*, uses a multidimensional exploratory factor analysis under item response paradigm to validate the behavioral framework of care partners' engagement in FRM using data from two linked U.S. nationally representative datasets, the National Health and Aging Trends Study (NHATS) 2015 and National Study of Caregiving (NSOC) 2015. To validate the framework, this paper examines (1) the prevalence of FRM behaviors, (2) how the prevalence of FRM behaviors differs between primary and secondary care partners, (3) the dimensionality of FRM behaviors based on how they are adopted simultaneously by dementia care partners; and (4) how the dimensionality of FRM behaviors differs between primary and secondary care partners. This paper validates and modifies the framework proposed in paper one and provides essential guidance for future measurement, research, and intervention development when engaging primary and secondary care partners to manage fall risk for community-dwelling OLWD.

The third paper, *Care partners' fall risk management and fall-related outcomes among community-dwelling older adults living with dementia*, examines the associations between care partners' FRM behaviors and fall-related outcomes among community-dwelling OLWD using longitudinal analysis. Utilizing longitudinal data NHATS 2015-2016 and the linked care partner dataset NSOC 2015, this study examines 1. the associations between care partners' individual FRM behaviors and OLWD's fall-related outcomes, 2. the associations between each domain of FRM behaviors and OLWD's fall-related outcomes, and 3. how the associations between care partners' FRM

behaviors and OLWD's one-year fall outcomes vary by OLWD's history of falls. This analysis aims to identify areas where care partners may have potential contributions in fall risk reduction and areas where they may need more training and support.

As a whole, these research results have implications for identifying possible points of intervention to improve current dementia services, public health services for older adults, and their care partners. Additionally, the social work perspective elevates the importance of caring labor, preventive care, and home and community-based services in current healthcare and long-term care systems for OLWD and advocates for social justice when distributing and supporting care responsibilities for OLWD.

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## **PAPER ONE.**

### **DEMENTIA CARE PARTNERS' FALL RISK MANAGEMENT: DEVELOPING A BEHAVIORAL FRAMEWORK USING A GROUNDED THEORY APPROACH**

#### **Introduction**

Falls and dementia are among the most prevalent and debilitating health issues that hinder older adults' capability to age in place. Approximately 30% to 40% of community-dwelling adults 65 years and older fall annually (Bergen, 2016; Morrison et al., 2012). It was estimated one in ten older adults in the United States lived with dementia (Hudomiet et al., 2018). Older adults living with dementia (OLWD) experience nearly two to ten times higher fall risk than persons without dementia (Allan et al., 2009) due to various biological, cognitive, and behavioral risk factors for falls (Allali & Verghese, 2020; Whitney et al., 2012). Furthermore, they are also more likely to be injured (Ek et al., 2018) and less likely to recover (Horgan et al., 1998; Huang et al., 2015; Shaw & Kenny, 2001), which contribute to a higher rate of institutionalization (Morris et al., 1987) and mortality (Baker et al., 2011). Moreover, falls are the second leading cause of hospital readmission for those living with cognitive impairment (Hoffman et al., 2019).

In the United States, most OLWD at home are cared for by informal care partners (broadly defined as their family, partners, friends, neighbors, or other unpaid care partners) (Hebert et al., 2013). Fall incidents and fall risk for OLWD often result in heightened care burden (Kamiya et al., 2014), emotional difficulties (Leggett et al., 2018), and constant fear and worries (Zhou, Strayer, et al., 2020) for OLWD's care partners.

Despite the severity of this issue, dementia and falls are both under-diagnosed and under-addressed in current healthcare systems. Among those who fall, less than half of them inform their healthcare providers (Stevens et al., 2012). Similarly, more than half of people living with dementia in the community are not detected (Connolly et al., 2011; Iliffe et al., 2009). A recent study showed that the most common unmet needs for community-dwelling OLWD is home/personal safety (97.4%) (Black et al., 2019). However, there are limited evidence-based fall prevention programs for community-dwelling OLWD (Peek et al., 2018), pointing to an urgent need to develop feasible and effective strategies to address the risk of falling among community-dwelling OLWD.

Previous studies suggest that care partners may play an essential role in managing fall risk for community-dwelling OLWD (Meyer et al., 2015; Zhou, Strayer, et al., 2020). For example, a study in the United States showed that high levels of informal care receipt were associated with a 54% reduction in risk of fall-related injuries among older adults living with cognitive impairment (Hoffman et al., 2017). This finding suggests that supporting care partners' fall risk management (FRM) is a possible effective strategy to reduce fall risk for community-dwelling OLWD.

There are tools and interventions developed to support or involve care partners in managing fall risk for people living with dementia, including an inclusive decision-making discussion tool for falls prevention (Meyer et al., 2019), a Home Safety Toolkit (Horvath et al., 2013) and a dyadic Tai Chi exercise program (Yao et al., 2013). However, none of these studies examined the impact of these interventions on engaging care partners' FRM. Only one study revealed some reasons for care partners' disengagement in FRM, including care partners' lack of motivation to undertake a home exercise program, reluctance to make environmental modifications, and competing priorities. It

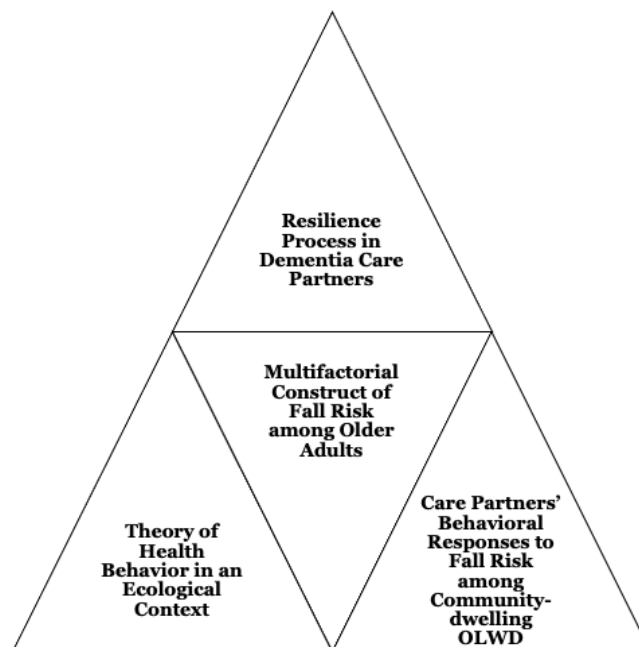
is unknown if these interventions can effectively engage dementia care partners to reduce fall risk for community-dwelling OLWD. This may be because these interventions are not grounded in a conceptual framework and empirical evidence about the role of dementia care partners in managing fall risk in community-dwelling OLWD.

A 2020 systematic review found that care partners adopted multi-level efforts in managing fall risk for community-dwelling OLWD, such as keeping them company, installing assistive technology, and getting trained by care providers; these findings, however, were based on studies that were not designed to systematically examine dementia care partners' FRM and the impact of care partners on fall risk reduction (Zhou, Strayer, et al., 2020). These gaps suggest the need to develop a comprehensive framework of care partners' FRM. Such a framework will therefore be used to identify modifiable targets for developing interventions that are built upon care partners' roles in FRM. These interventions can improve care partners' existing efforts that are beneficial, increase adoptions of other behaviors that are underutilized, and modify behaviors that can be harmful to OLWD or care partners themselves.

The purpose of this article is to present a framework of dementia care partners' FRM. It was developed using three steps. First, various theories were identified that were relevant to the study purpose to inform the development of this framework. These relevant theoretical resources and theoretical concepts were integrated to inform a qualitative study using a grounded theory approach with semi-structured, in-depth interviews to examine how care partners engaged in FRM for community-dwelling OLWD. Lastly, findings from the qualitative study were used to propose a framework of dementia care partners' FRM. After presenting these steps, the limitations and implications of this framework and how it could inform future studies were described.

## Theoretical Framework

The development of a framework of dementia care partners' FRM, which was reported here, was informed by four primary sources: (1) the multifactorial construct of fall risk among older adults (Casey et al., 2020; Katz, 2011; Rubenstein, 2006); (2) the construct of resilience process in dementia care partners - a process through which care partners utilize and are impacted by internal and external resources (Zhou, Ishado, et al., 2020); (3) the theory of health behavior in an ecological context (Simons-Morton, 2013), especially the concepts of “help-related behaviors” and “protective behaviors”; and (4) previous empirical evidence of care partners' behavioral responses to fall risk among community-dwelling OLWD (Zhou, Strayer, et al., 2020). (See Figure 1.1)



*Figure 1.1.* The theoretical framework that informs the study

### **Multifactorial Construct of Fall Risk among Older Adults**

The literature on fall risk has characterized the consequences, causes, and treatment of falls as “multifactorial”(Casey et al., 2020; Katz, 2011; Rubenstein, 2006). Falls in older adults often result from intrinsic and extrinsic risk factors. Intrinsic risk

factors are factors within the individual, such as mobility and balance issues, poor vision, muscle weakness, older age, underweight, and incontinence (Paliwal et al., 2017; Rubenstein, 2006). Extrinsic risk factors are those external to the individual, such as home hazards, lack of social support, unsafe neighborhood environment, inadequate staffing, and inappropriate clinical and administrative policies (Chippendale & Boltz, 2015; Feldman & Chaudhury, 2008; Høst et al., 2011; Kehinde et al., 2014). In contrast to the lack of social support, availability of and support provided by care partners can be a possible protective factor that is associated with fall risk reduction (Ang et al., 2019; Hoffman et al., 2017). However, this framework does not demonstrate how care partners' behavior and fall risk among OLWD are associated.

### **Resilience Process in Dementia Care Partners**

To explore the association between care partners and fall risk among OLWD, I integrated the construct of the resilience process in dementia care partners (Zhou, Ishado, et al., 2020) . This construct allowed the study to focus on the process through which care partners utilize and are impacted by internal resources (e.g., physical capacities, knowledge, self-efficacy) and external resources (e.g., financial support, social support) to manage fall risk for OLWD (Zhou, Ishado, et al., 2020). Informed by this theoretical construct, the focus of the study would be the process through which dementia care partners adopt different behaviors to manage fall risk (Zhou, O'Hara, et al., 2020). However, it is unclear what behaviors of dementia care partners are relevant to FRM for community-dwelling OLWD.

### **Theory of Health Behavior in an Ecological Context**

To develop strategies to identify care partners' behaviors that are relevant to fall risk reduction for OLWD, the theory of health behaviors in an ecological context was

incorporated (Simons-Morton, 2013). According to this theory, health promotion programs should focus not only on modifying health behaviors in a population at risk but also changes in (1) *health-related behaviors* taken by proximal others that directly affect this population, although usually not intentionally, and (2) *health-protective behaviors* that are undertaken intentionally to foster this populations' health. This theory guides the exploration of behaviors that dementia care partners intentionally and unintentionally adopt relevant to FRM (Simons-Morton, 2013).

### **Care Partners' Behavioral Responses to Fall Risk among Community-dwelling OLWD**

Since care partners might also adopt behaviors that support FRM without intending to have that impact, a list of FRM behaviors based on existing literature, including care partners' multi-level efforts in FRM, was developed (Zhou, Strayer, et al., 2020). This list allowed the study to examine behaviors that care partners might adopt for other reasons without knowing their associations with FRM. The list includes care partners' individual level (e.g., keep older adults company, medication management), interpersonal level (e.g., change the living arrangement, socially withdraw), physical environment level (install assistive technology, conduct home modification), and community/institutional level efforts (e.g., receiving training, collaborating with professional healthcare team members).

## **Methods**

### **Study Design**

Guided by the theoretical framework proposed above, this study aims to identify care partner behaviors associated with FRM for community-dwelling OLWD and propose a behavioral framework for conceptualizing and organizing these behaviors.

The analysis used data from a qualitative study of 14 semi-structured, in-depth interviews conducted from July 2019 to March 2020 as part of a larger study focused on dementia care partners' perceptions and experiences of FRM in Washington State. The parent study used a grounded theory approach (Bryant & Charmaz, 2019) to examine care partners' perceptions, behaviors, facilitators, and barriers about managing fall risk for community-dwelling OLWD. The qualitative method was selected for a systematic exploration of care partners' experiences in FRM, which was not captured in prior literature (Zhou, Strayer, et al., 2020). The grounded theory approach was chosen for its suitability in generating new perspectives from familiar phenomena, developing a new framework from individual experiences, and its focus on the interactive processes between individuals and the environment (Aldiabat & Navenec, 2011; Charmaz, 2014). This research was approved by the Institutional Review Board at the University of Washington.

### **Sampling and Recruitment**

Participant inclusion criteria were adult family members, friends, neighbors, or other unpaid care partners who have provided support or care in the past two years for at least one community-dwelling OLWD. Criteria for community-dwelling OLWD were (1) 55 years or older; (2) care partner reported that a health care provider told them that the patient had dementia; (3) older adults scored 2 or higher on the "Eight-item Interview to Differentiate Aging and Dementia (AD-8 dementia screening tool) (Cordell et al., 2013)" based on care partners' report; and (4) OLWD lived at home or in independent settings, not skilled nursing facilities, assisted living facilities, or adult care home.



A purposive sampling method, the maximum variation sampling approach (Etikan et al., 2016) was used to select participants based on a broad scope of information obtained from them (Creswell et al., 2007; Fassinger, 2005; Patton, 1990). Therefore, this approach could result in a more comprehensive theoretical model. It is also helpful in identifying and clarifying the common themes across different participants' experiences (Patton, 1990). Therefore, a variety of care partners based on gender, age, race/ethnicity, education level, their relationships with OLWD, different stages of the dementia care trajectory, and their fall history of older adults were intentionally included. This information was collected in the eligibility screening interview. To maximize variation of care partners' experience included in the study, participants were asked if there was(were) other care partner(s) who provided support to the older adult they were currently supporting. If so, participants were asked about other care partners' FRM behaviors based on their observations of other care partners.

Community outreach methods were used to recruit care partners from settings throughout Washington State, outpatient clinics for OLWD, community service organizations, and public health departments. Individuals who met inclusion criteria were invited to participate or voluntarily contact the researcher. All participants gave consent to participation.

### **Data Collection**

The semi-structured, in-depth interview method was chosen as it could provide a valuable opportunity to explore care partners' experiences across time, from past to the present, while also allowing the study to examine FRM behaviors that care partners unintentionally adopted. Interviews lasted about half an hour and four hours with an average of 90 minutes and were digitally recorded. Interviews were conducted in care

partners' homes or by phone. After the first interview, I asked for permission to call the participants back if there were some supplementary questions. Two care partners were called back with follow-up questions and these follow-up interviews lasted about half an hour to one hour. After the completion of all the data collection processes, care partners received a \$50 gift card to compensate for their time.

Interview questions related to the study aim were informed by the theoretical framework presented in Figure 1.1. Care partners were asked about their experiences and opinions regarding:

- What behaviors they have adopted to manage fall risk for community-dwelling OLWD since they became aware of their fall risk.
- What behaviors they have adopted that they believe are relevant to FRM.
- Whether they have adopted any behaviors on the list (if they did not mention these behaviors when responding to the first two questions) based on previous literature or interviews conducted with other care partners; the list of behaviors was expanded during the process of data collection when care partners mentioned any behaviors that were not included in previous literature (Zhou, Strayer, et al., 2020). This updated list was used in the interviews with new participants.
- If OLWD have additional care partners, what they have done to manage fall risk; since all the included participants were primary care partners who took the primary responsibilities of supporting OLWD, these additional care partners were defined as secondary care partners.

## **Data Analysis**

All interviews were transcribed. The transcriptions were uploaded in Atlas.ti 9.0.5. The coding process was guided by the grounded theory to facilitate the development of the behavioral framework. The coding procedure followed the grounded theory approach's open coding, memory ("memo") writing, axial coding, and constant comparative process (Charmaz, 2014; Corbin & Strauss, 2014).

I first conducted open coding to identify different types of FRM behaviors, resulting in 234 open coding categories. I also wrote memos for each code regarding (1) if this behavior was conducted by participants or secondary care partners, (2) if this behavior was adopted intentionally or unintentionally for FRM, and (3) a summary of how this code was related to the original data and other codes.

Following open coding, I conducted axial coding to categorize different behaviors to generate a preliminary behavioral framework. I included both frequent codes and infrequent codes of FRM behaviors to develop a comprehensive understanding of these care partners' behaviors.

Last, using the constant comparative process, I compared the preliminary behavioral framework proposed from axial coding with interview data, memos, and relevant literature to further refine the behavioral framework and develop definitions for each behavior category. I conducted comparisons between behaviors that were intentionally and unintentionally adopted by primary care partners. Intentional FRM behaviors were those behaviors care partners adopted to manage fall risk. Unintentional FRM behaviors were those care partners adopted for reasons other than managing fall risk. The numbers of OLWD's primary care partners who adopted each behavior were summarized. Behaviors of secondary care partners were only collected through

interviewing primary care partners, so not all secondary care partners' intentions could be assessed. For this reason, secondary care partners' FRM behaviors were not categorized based on their intentions.

## **Results**

### **Participants**

A sample of 14 care partners lived across four counties in Washington State (San Juan, King, Snohomish, and Spokane). There were some variabilities across factors that might impact their caregiving processes, such as gender, age, education attainment, and race/ethnicity of both care partners and OLWD (Table 1.1).

Care partners reported that half of the older adults lived with Alzheimer's Disease (n=7), and others live with Parkinson's dementia (n=2), Vascular dementia (n=1), dementia with Lewy bodies (n=1), Frontotemporal dementia (n=1), and unspecified dementia (n=2). The majority of older adults lived with mild (n=4) or moderate (n=6) dementia. All the OLWD were ambulatory, with or without walking aids and other assistance. Twelve out of 14 OLWD had a fall history. Per care partners' reports, OLWD had a diagnosis of dementia from 6 months to eight years. The majority of them (n=13) lived together with care partners and/or other families.

The study included both spouse/partner care partners (n=7) and adult children (n=7). All 14 care partners interviewed are primary care partners based on their own definition. They were asked if there were other people who also supported the OLWD and what behaviors other care partners adopted for FRM. Seventeen secondary care partners' behaviors were reported by the primary care partners.

Table 1.1 Characteristics of participants

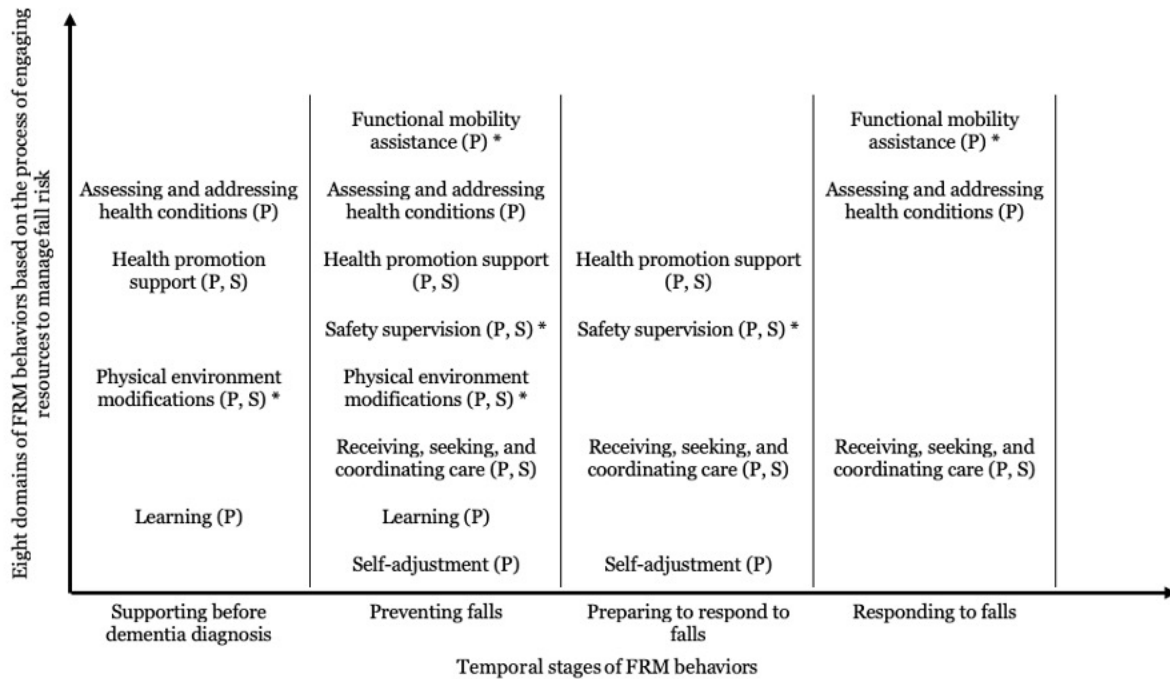
| Characteristics                                                                                 | Mean(range)/ n <sup>a</sup> (%) |
|-------------------------------------------------------------------------------------------------|---------------------------------|
| <b>Care partners (n=14)</b>                                                                     |                                 |
| Age                                                                                             | 69 (48-87)                      |
| Gender (% female)                                                                               | 11 (79%)                        |
| Education (% College degree or above)                                                           | 9 (64%)                         |
| <b>Race/Ethnicity</b>                                                                           |                                 |
| Non-Hispanic White                                                                              | 10 (71%)                        |
| Black                                                                                           | 1 (7%)                          |
| Hispanic                                                                                        | 1 (7%)                          |
| Mix (Filipino and Non-Hispanic White)                                                           | 1 (7%)                          |
| Not reported                                                                                    | 1 (7%)                          |
| <b>Relationship to older adults with dementia</b>                                               |                                 |
| Spouse /partner                                                                                 | 7 (50%)                         |
| Adult child                                                                                     | 7 (50%)                         |
| <b>Primary care partners</b>                                                                    | 14 (100%)                       |
| <b>Primary care partners who have secondary care partners</b>                                   | 9 (64%)                         |
| <b>Number of secondary care partners reported by primary care partners</b>                      | 17                              |
| <b>Older adults living with dementia who care partner study participants reported on (n=14)</b> |                                 |
| Age                                                                                             | 82 (69-95)                      |
| Gender (% female)                                                                               | 9 (64%)                         |
| Education (% College degree or more)                                                            | 9 (64%)                         |
| <b>Race/ethnicity</b>                                                                           |                                 |
| Non-Hispanic White                                                                              | 11 (79%)                        |
| Black                                                                                           | 1 (7%)                          |
| Multiracial (Non-Hispanic White and Latinx)                                                     | 1 (7%)                          |
| Not reported                                                                                    | 1 (7%)                          |
| <b>Dementia types</b>                                                                           |                                 |
| Alzheimer's disease                                                                             | 7 (50%)                         |
| Parkinson's dementia                                                                            | 2 (14%)                         |

Table 1.1. continued

|                                                                |                     |
|----------------------------------------------------------------|---------------------|
| Vascular dementia                                              | 1 (7%)              |
| Frontotemporal dementia                                        | 1 (7%)              |
| Dementia with Lewy bodies                                      | 1 (7%)              |
| Unspecified dementia                                           | 2 (14%)             |
| <b>Dementia stage</b>                                          |                     |
| Mild                                                           | 4 (29%)             |
| Moderate                                                       | 6 (43%)             |
| Severe dementia                                                | 1 (7%)              |
| Don't know                                                     | 3 (21%)             |
| <b>Had Fall History (Per care partner report)</b>              | 12 (86%)            |
| <b>Time of dementia diagnosis</b>                              | 3.8 (0.5 – 8) years |
| <b>Living arrangement</b>                                      |                     |
| Living together with care partners and/or other family members | 13 (93%)            |
| Living alone                                                   | 1 (7%)              |

### A Behavioral Framework for Care Partners' FRM

Informed by the theoretical framework (Figure 1.1), a behavioral framework was developed through open coding, memo writing, axial coding, and the constant comparison process (Figure 1.2). There are two dimensions of this behavioral framework. The first is the process of engaging resources to manage fall risk. This process involves (1) eight domains of FRM behaviors, (2) responsibility allocations among primary and secondary care partners, and (3) behaviors that dementia care partners intentionally and unintentionally adopt to manage fall risk. The second dimension is the temporal stages of FRM, including (1) supporting before dementia diagnosis, (2) preventing falls, (3) preparing to respond to falls, and (4) responding to fall. At different stages during the process of FRM, care partners might adopt different behaviors.



**Figure 1.2.** A behavioral framework for dementia care partners' fall risk management

*Note:* P represents this behavior was adopted by primary care partners in the study; S represents this behavior was adopted by secondary care partners in the study; \* represents this behavior was often adopted intentionally for fall risk management; those without \* were often adopted unintentionally.

## **1. Process of engaging resources to manage fall risk.**

### **1.1 Eight domains of FRM behaviors.**

Based on the theoretical framework of the study, especially the construct of the resilience process for dementia care partners, eight domains of dementia care partners' FRM behaviors were identified (Table 1.2). These are (1) functional mobility assistance, (2) assessing and addressing health conditions; (3) health promotion support; (4) safety supervision; (5) physical environment modification; (6) receiving, seeking, and coordinating care; (7) learning; and (8) self-adjustment. Definitions of each domain and behavioral items were generated.

Table 1.2. Eight domains of dementia care partners' fall risk management behaviors adopted by primary care partners (intentionally and unintentionally) and secondary care partners

| Domains                                           | Definitions                                                                                                                                                                       | Behavior items <sup>a</sup>                   | # of OLWD receiving such support from |                     | # of OLWD receiving such support from secondary CP |
|---------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------|---------------------------------------|---------------------|----------------------------------------------------|
|                                                   |                                                                                                                                                                                   |                                               | Inten-<br>-tional                     | Uninten-<br>-tional |                                                    |
| <b>Functional mobility assistance</b>             | Physically or verbally assist older adults with dementia to move around in the environment in order to participate in the activities of daily living safely (Forhan & Gill, 2013) | Standing assistance                           | 6                                     | 1                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Walking assistance                            | 7                                     | 1                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Toileting assistance                          | 2                                     | 0                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Shower/bath assistance                        | 1                                     | 1                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Hazard reminder                               | 4                                     | 0                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Mobility restraint                            | 3                                     | 0                   | 0                                                  |
| <b>Assessing and addressing health conditions</b> | Assess and address older adults with dementia's mental and physical health conditions directly                                                                                    | Assess physical and mental health conditions  | 12                                    | 7                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Address physical and mental health conditions | 5                                     | 3                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Medication management                         | 2                                     | 10                  | 2                                                  |
| <b>Health promotion support</b>                   | Care partners enable older adults with dementia to increase control over and to improve their health (Woodall & Freeman, 2020)                                                    | Health and risk communication                 | 12                                    | 1                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Enhance activity engagement                   | 5                                     | 7                   | 5                                                  |
|                                                   |                                                                                                                                                                                   | Exercise support                              | 3                                     | 7                   | 4                                                  |
|                                                   |                                                                                                                                                                                   | Diet support                                  | 2                                     | 14                  | 5                                                  |
|                                                   |                                                                                                                                                                                   | Improve and maintain self-efficacy            | 3                                     | 2                   | 1                                                  |
|                                                   |                                                                                                                                                                                   | Improve help-seeking behaviors                | 2                                     | 1                   | 0                                                  |
| <b>Safety supervision</b>                         | Being able, ready, and willing to perform intentional acts to reduce injury risk to a less capable person. (Wills et al., 1997)                                                   | Pay close attention                           | 8                                     | 1                   | 0                                                  |
|                                                   |                                                                                                                                                                                   | Regular check-in                              | 2                                     | 0                   | 2                                                  |
|                                                   |                                                                                                                                                                                   | Be present                                    | 5                                     | 1                   | 5                                                  |



Table 1.2. Continued.

|                                                  |                                                                                                                                                                      |                                                        |    |    |   |
|--------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|----|----|---|
| <b>Physical environment modification</b>         | Modify the physical aspect of the environment that OLWD interact with.                                                                                               | Home safety assessment, modification, and organizing   | 12 | 2  | 4 |
|                                                  |                                                                                                                                                                      | Ensure the safety of shoes/socks                       | 2  | 0  | 0 |
|                                                  |                                                                                                                                                                      | Support use of mobility assistive technology           | 6  | 2  | 3 |
|                                                  |                                                                                                                                                                      | Support use of monitoring technology                   | 4  | 0  | 0 |
| <b>Receiving, seeking, and coordinating care</b> | Receive, seek, and coordinate formal and informal care and services                                                                                                  | Use of informal care                                   | 6  | 4  | 4 |
|                                                  |                                                                                                                                                                      | Hire and coordinate with paid caregivers               | 0  | 2  | 0 |
|                                                  |                                                                                                                                                                      | Use of social and health services                      | 8  | 13 | 2 |
|                                                  |                                                                                                                                                                      | Communicate with other care partners and professionals | 4  | 0  | 1 |
| <b>Learning</b>                                  | Gain information, knowledge, and skills from past experience and the outside world about fall risk management for OLWD (Zhou, et al, 2020)                           | Learn from professional care providers                 | 8  | 6  | 1 |
|                                                  |                                                                                                                                                                      | Learn from care partners' life experiences             | 8  | 4  | 0 |
|                                                  |                                                                                                                                                                      | Learn from older adults with dementia                  | 6  | 2  | 0 |
|                                                  |                                                                                                                                                                      | Learn from social network                              | 6  | 5  | 0 |
|                                                  |                                                                                                                                                                      | Learn online and media                                 | 3  | 1  | 0 |
| <b>Self-adjustment</b>                           | Care partners change their arrangements of living, sleeping, working, and social and physical activities in response to the fall risk of older adults with dementia. | Change living arrangement                              | 0  | 4  | 0 |
|                                                  |                                                                                                                                                                      | Change sleeping arrangement                            | 1  | 0  | 0 |
|                                                  |                                                                                                                                                                      | Reduce working time                                    | 1  | 1  | 0 |
|                                                  |                                                                                                                                                                      | Avoid social activities                                | 0  | 5  | 0 |
|                                                  |                                                                                                                                                                      | Adapt walking behaviors                                | 4  | 0  | 0 |

Note: Definitions for behavior items were reported in the text, not in the table.

### *Function mobility assistance.*

Care partners reported efforts they made to physically or verbally assist OLWD to perform movements in the environment in order to safely participate in the activities of daily living (Feldman & Chaudhury, 2008; Forhan & Gill, 2013). These efforts included

assistance to stand, walk, use the toilet, and take a shower/bath. Sometimes, they provided this assistance even though the OLWD were still capable of participating in these activities alone but had a high risk of falling. For example, this care partner explained:

I noticed she tried to lean forward on the toilet and fall off. ...I would come to the door and ask her if she needs my help. I could see the lessening of the anxiety when she saw I was there. I would let her do whatever she could do on her own but took over when she was about to fall. (Daughter: age 60; OLWD: age 92)

As OLWD also experienced various cognitive and sensory impairments, care partners needed to provide hazard reminders, especially when OLWD went outdoors. One care partner said, “When we were out, I just tried to, particularly on the sidewalk, stay right beside him. I would say, oh, there is an irregular place here. Or you need to step up here, you know, just some verbal cues to him.” (Wife: age 80; OLWD: age 79).

When care partners were not able to provide the assistance mentioned above, they would restrain OLWD from going out or doing activities alone. One daughter shared about the types of conditions where she would restrain her mom’s mobility: “If she walks outside for any distance, I wouldn’t allow her to do that by herself.” (Daughter: age 75; OLWD: age 95) Some care partners also tried to restrain/limit OLWD’s activities during the sleeping time when they might not be able to provide immediate assistance.

#### *Assessing and addressing health conditions.*

Care partners made various efforts in assessing and addressing OLWD’s mental and physical health conditions, which were relevant to older adults’ risk of falling, such as visual impairment, arthritis, gait, mobility impairment, fatigue, depression, spatial

awareness, declining cognitive functions, cancer, urinary tract infections, risk of heart failure, diabetes, and injuries after falls.

One wife shared that she noticed many symptoms of her husband that raised her concern about the risk of falling: “Not like other older adults might fall because their body is frail. He just couldn't have control over his body. He just forgot the mechanics of how to move his body. I could see this would make him fall in the future.” (Wife: age 66; OLWD: age 69).

In everyday life, care partners often managed medication to address older adults' chronic conditions (e.g., diabetes, heart diseases, pains) and behavioral and psychological symptoms of dementia (BPSD) (e.g., aggressiveness, anxiety, and depression) that might be relevant to OLWD's fall risk. Some care partners used other strategies, such as providing psychosocial support or nonpharmacological approaches. For example, after one OLWD received a cancer diagnosis, he experienced symptoms of depression and started not to pay attention to the surroundings and how to walk. His wife tried to provide support during this challenging time. She explained:

I certainly understood if he was facing his own death that he would be distracted by it. Most people would. I didn't regret that feeling in him, but I kept saying, I hear what you are saying, and I'll support whatever you want. Are you sure that's really where you want to go? Are you okay dying now? It was just a conversation about death and dying and discussing things that he wants to do or not to do before he dies. Now he is back to his old self.” (Wife: age 80; OLWD: age 79).

In another example, one daughter used nonpharmacological approaches to manage OLWD's BPSD: “Sometimes when she is more tired, she becomes more anxious and not collaborative to walk, eat, or take meds. So, I use my lavender diffuser all the time to keep her calm. She likes music so I play music. These help a lot.” (Daughter: age 66; OLWD: age 81)”. Some care partners explained how they utilized other non-

pharmacological approaches, such as art activities, gardening, and outdoor activities in nature to address OLWD's psychological and behavioral symptoms.

*Health promotion support.*

Besides assessing and addressing health issues that OLWD encountered, care partners also made a variety of efforts to support OLWD's health promotion behaviors, which was defined as enabling OLWD to increase control and to improve their own health (Woodall & Freeman, 2020). These efforts included health and risk communication, enhancing OLWD's activity engagement, exercise support, diet support, improving and maintaining OLWD's self-efficacy, and improving their help-seeking behaviors.

Care partners played an important role in communicating health and risk issues with older adults to support them in adjusting their behaviors and making decisions. They provided instructions to adjust their walking habits, taught them how to fall and how to get up after falling, discussed the importance and potential ways they could address fall risk, and modeled new behavioral changes. One daughter explained how she instructed her mom to learn how to get up:

One time she fell, and I told her, I'm not going to help you up. I'm here, but you have to know what to do in case you're alone. I don't want you to lay on the floor if you're not hurt and you're able to get up. Now she can do that. (Daughter, age 58; OLWD: age 94)

Exercise and healthy nutrition are critical components of health promotion and FRM. These were areas that care partners often played a vital role in their everyday lives, such as care partners' taking older adults out for a walk, reminding older adults to walk around in the house, and ensuring they eat on time.

Another type of health promotion effort that some care partners viewed as important in FRM was to enhance activity engagement, which was, supporting OLWD's

participation, spending time, and gaining positive affective experiences in everyday activities (Newton et al., 2016). It might require care partners to modify these activities to adapt to older adults' cognitive and physical functions. For instance, one daughter shared how she tried to be creative to transform the meaning of older adults' psychological and behavioral symptoms:

One day, my mom suddenly started pulling everything out of the freezer. When she did it, I said, oh, let's wipe it down now. I know the freezer didn't need to be cleaned out. But who cares? We wiped it down. And then she put everything back in. We had a super fun afternoon. (Daughter care partner: age 60; OLWD: age 92)

The daughter further explained how these creative activity engagements made her mom feel her daughter accepted her limitations; therefore, her mom felt more comfortable asking her daughter for help in risky situations.

Care partners also made efforts to improve older adult's self-efficacy. One care partner explained that he thought taking his wife out to her favorite restaurant was related to improving OLWD's self-efficacy, therefore, reducing her risk of falling: "It makes her feel good about herself. And I think that helps. I think it makes her mind say - I'm good. I'm okay. I think it gives her a little confidence. We all need a boost of confidence from time to time." (Husband: age 71; OLWD: age 73)

Care partners also struggled to improve OLWD's help-seeking behaviors. One care partner suggested the most important thing for FRM is to "be realistic about your limits and don't be embarrassed to ask others to help you." (Husband, age 85, OLWD, age 83) Another daughter shared how she came up with ways to encourage her dad (OLWD) to ask for help:

My dad can fall and stay on the ground for two hours, even though he got the fall alert. He thought, well, I can do this myself. This is the hardest part for him even though I kept asking him, why don't you call us for help? He

always thought I don't wanna be a burden. I saw a thing, so I printed it out to put in dad's bathroom – “You are not a burden. You are carrying a burden, which, by definition, you cannot do alone.” (Daughter: age 60; OLWD: male, age 83)”

These examples of care partners' behaviors in supporting OLWD's health promotion showed that they not only provided direct assistance, but also helped cultivate resilience in OLWD and enhance OLWD's capacity in improving their health and well-being.

*Safety supervision.*

Because fall events are often unpredictable, care partners also made extensive efforts in safety supervision for OLWD, defined as “being able, ready, and willing to perform intentional acts, such as restraint, guidance, modeling, or instruction, as needed to reduce injury risk to a less capable person. (Wills et al., 1997)”. It includes three behavioral indicators - paying close attention, regular check-in, and being present.

Paying close attention refers to care partners' efforts to keep OLWD in sight constantly, especially when older adults are moving and doing anything that might have high fall risk, such as taking a bath, or carrying things. Care partners often used this strategy especially when OLWD did not accept assistance. One care partner described the strategies that she used to pay close attention to OLWD but not be noticed:

I tried not to do it too much because she (my mom) still likes being independent. And that would irritate her if I constantly helped her with everything. I'd make sure that if she was walking from the bathroom to the front door to the kitchen, I would strategically sit here if she is wobbly. (Daughter: age 60; OLWD: age 92)

When care partners had to leave OLWD alone, care partners used regular check-ins to ensure older adults' needs are met (if they have access to water and food), and to check if they fell and required medical care. A daughter described how she always tried to call to check-in on OLWD when she was away: “When I leave, I always call to check

on her. She could fall and nobody is able to be here for the doors locked and just not eating properly.” (Daughter: age 75; OLWD: age 95)

Sometimes, care partners believed that just being present with the OLWD could help prevent falls as their presence would bring a sense of safety for older adults. After reviewing all her efforts, one daughter suggested: “I think the most important thing that I did all around was make her happy and make her feel safe. ... I don't know if she worried or not, but I believe she knew on some level that I was there for her. You can see that peace on her face.” (Daughter: age 60; OLWD: age 92) This example explained how care partners’ presence itself might be relevant to reducing OLWD’s fear of falling and risk of falling.

*Physical environment modification.*

Care partners made various efforts to modify physical aspects of OLWD’ environment, including physical aspects of the home, shoes/socks, mobility assistive technology (such as cane, walker, wheelchair), and monitoring technology.

Care partners’ efforts in modifying the home environment includes not only large-scale modifications of stairs, rugs, and bars but also continuous organizing. One care partner emphasized the importance of keeping the home environment tidy, such as picking up things that OLWD drops in order to reduce tripping hazards.

For mobility assistive technology, care partners selected and made decisions about which type of technology older adults should use and also persuaded, encouraged, and reminded older adults to use it in everyday lives. One daughter shared how she was able to persuade her mom to feel comfortable using a walker:

Her goal is to not use the walker. You know, I tell her that she probably will be using the walker for the rest of her life and that she needs to look at it as a tool and she's still the boss. That's why we call it the wheels. I tell her this is only a tool if you're doing the work. Just making sure that you

stay, do your job of keeping on your feet. (Daughter care partner, age 58; OLWD: female, age 79)

Monitoring technology included Global Positioning System (GPS) tracking via cell phone, fall alert buttons that connect with care partners and emergency medical services, and sensors on the door. Care partners were often the ones who looked for information, purchased, prescribed, and installed these monitoring technology tools. For example, one care partner explained how she researched a lot of companies online and consulted with her mom (OLWD)'s neighbors to get a fall alert for her mom, who lived in a remote area. After attaining the technology, care partners also needed to make efforts to ensure older adults use these tools.

*Receiving, seeking, and coordinating care.*

Fall risk management's complexity required care partners to receive, seek, and coordinate different types of care and services, such as informal care, paid caregivers, and social and health services.

Care partners often received and asked for help from other families or friends, especially when they were not present. They also discussed OLWD's health conditions and prepared for older adults' emergency needs with other care partners. One care partner described the arrangements she made in order attend a dementia caregiver conference:

So, I left at 8:30 am. And our neighbor came over at 10. One of my girlfriends came over at 11:30 and one of my other girlfriends came over at one. And then our neighbor came back over at 2:30. So everyone and a half-hour someone came over. If she was to fall and break a hip or something, yeah, and we wouldn't want her to lay there for six hours. (Daughter: age 58; OLWD: age 94)

Care partners also hired and coordinated with paid caregivers to provide company to older adults, assist with household work, and enhance older adults' activities.



Besides working with paid caregivers, care partners often used social and health services for OLWD to address their fall risk (including health conditions related to fall risk) or fall events. These included taking older adults to community exercise or nutrition programs, accompanying older adults to doctor appointments, selecting physical therapists for older adults, purchasing personal trainers, looking for health services after older adults fell, and accessing hospice care.

Care partners not only received or sought help from other care partners or social and health providers, but also tried to communicate with them about OLWD's needs and improve their conditions. For example, this daughter tried to communicate with the other care partner (OLWD's wife), asking them to pay attention to OLWD's limitations and potential fall risk and adapt their behaviors:

I couldn't understand why my mom was acting that way. Like, "Why are you making dad (OLWD) do stuff that you know is gonna make him fall? Why are you...?" You know, she's had him out there helping her weed, and I tell her, "I don't want dad out there. He's gonna fall." (Daughter: age 60; OLWD: age 83)

Some care partners influenced professional service providers to pay attention to OLWD's high risk of falling. One daughter shared that how she was able to advocate for her mom when using services from a daycare center:

When they bring her off the daycare center bus, I expect them to assist her because she needs help. It's dark, but they didn't walk my mom up to the door. I think there is a risk of falling if she doesn't have assistance. So, I communicated with the staff on the bus.... I also asked them to provide the occupation therapy services to her as they promised. (Daughter: age 66; OLWD: age 85)

Care partners in those roles were not only helpers of OLWD but used their knowledge and experiences to challenge and improve the status quo of OLWD's social environment and social and health services provided to them.

*Learning.*

Since managing fall risk is a complicated process, care partners emphasized the importance of learning, gaining information, knowledge, and skills from lived experience and the outside world.

Some care partners learned how to manage fall risk from professional care providers, such as learning how to conduct exercises with OLWD:

We had an occupational therapist and physical therapist coming here. They taught me exercises to do with her (my mom) because they would come once or twice a week, but then other days that they were not here. I could do the exercise and that was excellent.” (Daughter: age 58; OLWD: age 94)

Care partners also described how they learned about fall risk from their own life experiences, such as caring for children, caring for other families, and even their own experiences of falling. One care partner learned how to fall from her own injury experiences following a car accident:

With my car accident, I mean, first I couldn't even walk for six months. And then I finally graduated from the wheelchair, but in the whole process of going through that, I was falling. Every single day, probably 15 times a day. And I had to learn how to mitigate. That's how I learned how to fall so I taught my mom how to do that when she fell. (Daughter, age 60; OLWD: age 92)

Care partners also reported how they learned about managing falls from OLWD. One daughter explained she learned from her mom a safer way to walk and then used this knowledge to continue to support her mom as dementia progressed. Social networks were another important resource for care partners to learn about FRM. One daughter care partner shared that for her, “The biggest thing is talking to people who have gone through it with their parents. They tell me different strategies that they use to help prevent falls.” (Daughter, age 60; OLWD: age 92) Another care partner learned from the media and the internet. These examples demonstrated that dementia care

partners had very diverse learning resources to develop their capacities in managing fall risk for OLWD.

*Self-adjustment.*

To manage falls, care partners sometimes needed to change their arrangements of living, sleeping, working, and social and physical activities. For example, one care partner decided to sleep in the same room with the OLWD after OLWD's fall incidents:

My mom told me that, when she came back to the bed to go to the bathroom, she fell. So I thought, I better come in the house. Then I slept on her bedroom floor. I thought I was gonna lose my mind for a while for about a month because I wasn't sleeping at all. (Daughter, age 58; OLWD: age 94)

Another important adjustment was care partners' changing their own walking habits and speed for OLWD. For instance, one care partner noticed at some point, she could no longer talk with OLWD while walking like they used to:

We were walking along, and I said, oh, I wanted to tell you that, tonight there's a program on TV. He said, wait a minute, I can't do two things at once. So, I've learned that, currently, when he's walking in, you cannot ask him questions, because he needs to concentrate on his gait and walking." (Wife, age 80; OLWD: age 79)

These examples demonstrated that care partners not only needed to provide support to OLWD but also required them to adjust their living arrangements and behaviors in response to OLWD's high risk of falling.

***1.2 Allocation of responsibilities between primary and secondary care partners.***

OLWD often had more than one care partner due to the complexity of their needs for assistance. This study found that, although primary care partners assumed the primary responsibilities of supporting OLWD, secondary care partners also provided various supports. Despite limited information, it was still noticeable that primary and secondary care partners demonstrated different behavioral patterns in FRM.

Primary care partners have adopted all eight domains of FRM. However, secondary care partners assisted in health promotion support (such as enhancing OLWD's activity engagement and providing exercise and diet support), safety supervision, physical environmental modification, and receiving, seeking, and coordinating care.

Notably, primary care partners did not report secondary care partners providing functional mobility assistance and conducting self-adjustment in response to OLWD's fall risk; and few primary care partners report secondary care partners learning behaviors and participating in assessing and addressing health conditions for OLWD. One primary care partner suggested how the secondary care partner might not know how to assist OLWD to walk outside: "She (my mom) was always in my head. I was always thinking ahead about how to make this accommodating when we went out. And I remember my siblings never did that as much. I mean, they did the best they could." (Daughter, age 60; OLWD: age 92) As this quote illustrates, primary and secondary care partners might have different experiences and expectations about the responsibilities of managing fall risk for OLWD.

### ***1.3. Categorization of intentional and unintentional FRM.***

Primary care partners' adoption of each FRM behavior is categorized as intentional and unintentional based on the purpose that care partners adopt those behaviors for. They often provided functional mobility assistance, safety supervision, and physical environment modifications that they stated were for managing fall risk.

In addition, care partners frequently adopted other FRM behaviors without realizing their relevance to FRM. These behaviors include assessing and addressing

health conditions, health promotion efforts (especially enhancing activity engagement, exercise support, diet support), and receiving, seeking, and coordinating care.

## 2. Temporal stages of FRM

Each FRM behavior might be adopted for different challenges specific to different stages of FRM. There are four stages of FRM: (1) supporting before dementia diagnosis; (2) preventing falls; (3) preparing to respond to falls; (4) responding to falls (Table 1.3).

Table 1.3. Temporal stages of fall risk management

| Domains                                           | Behavior items                                | Process of fall risk management |               |                             |                  |
|---------------------------------------------------|-----------------------------------------------|---------------------------------|---------------|-----------------------------|------------------|
|                                                   |                                               | Support before diagnosis        | Prevent falls | Prepare to respond to falls | Respond to falls |
| <b>Functional mobility assistance</b>             | Standing assistance                           |                                 | √             |                             | √                |
|                                                   | Walking assistance                            |                                 | √             |                             | √                |
|                                                   | Toileting assistance                          |                                 | √             |                             |                  |
|                                                   | Shower/bath assistance                        |                                 | √             |                             |                  |
|                                                   | Hazard reminder                               |                                 | √             |                             |                  |
|                                                   | Mobility restraint                            |                                 | √             |                             |                  |
| <b>Assessing and addressing health conditions</b> | Assess physical and mental health conditions  | √                               | √             |                             | √                |
|                                                   | Address physical and mental health conditions |                                 | √             |                             | √                |
|                                                   | Medication management                         |                                 | √             |                             |                  |
| <b>Health promotion support</b>                   | Health and risk communication                 |                                 | √             | √                           |                  |
|                                                   | Enhance activity engagement                   |                                 | √             |                             |                  |
|                                                   | Exercise support                              | √                               | √             |                             |                  |
|                                                   | Diet support                                  | √                               | √             |                             |                  |
|                                                   | Improve and maintain self-efficacy            |                                 | √             |                             |                  |
|                                                   | Improve help-seeking behaviors                |                                 | √             | √                           |                  |
| <b>Safety supervision</b>                         | Pay close attention                           |                                 | √             | √                           |                  |
|                                                   | Regular check-in                              |                                 | √             | √                           |                  |
|                                                   | Be present                                    |                                 | √             | √                           |                  |

Table 1.3. continued.

|                                                  |                                                        |   |   |   |
|--------------------------------------------------|--------------------------------------------------------|---|---|---|
| <b>Physical environment modification</b>         | Home safety assessment, modification, and organizing   | ✓ | ✓ |   |
|                                                  | Ensure the safety of shoes/socks                       |   | ✓ |   |
|                                                  | Support use of mobility assistive technology           | ✓ | ✓ |   |
|                                                  | Support use of monitoring technology                   |   |   | ✓ |
| <b>Receiving, seeking, and coordinating care</b> | Use of informal care                                   |   | ✓ | ✓ |
|                                                  | Hire and coordinate with paid caregivers               |   | ✓ |   |
|                                                  | Use of social and health services                      |   | ✓ | ✓ |
|                                                  | Communicate with other care partners and professionals |   | ✓ |   |
| <b>Learning</b>                                  | Learn from professional care providers                 | ✓ | ✓ |   |
|                                                  | Learn from care partners' life experiences             | ✓ | ✓ |   |
|                                                  | Learn from older adults with dementia                  |   | ✓ |   |
|                                                  | Learn from social network                              | ✓ | ✓ |   |
|                                                  | Learn online and media                                 | ✓ | ✓ |   |
| <b>Self-adjustment</b>                           | Change living arrangement                              |   | ✓ | ✓ |
|                                                  | Change sleeping arrangement                            |   | ✓ | ✓ |
|                                                  | Reduce working time                                    |   | ✓ |   |
|                                                  | Avoid social activities                                |   | ✓ |   |
|                                                  | Adapt walking behaviors                                |   | ✓ | ✓ |

### ***2.1 Supporting before dementia diagnosis.***

In the early stage of dementia, even before older adults experienced symptoms of dementia or received a diagnosis of dementia, older adults might not need care partners' assistance with activities of daily living. However, some care partners started to engage in the following domains of FRM behaviors: assessing physical and mental health conditions, exercise and diet support, physical environment modification, and learning-related behaviors. One care partner helped modify the home environment when her mom had a fall-related fracture before her mom was diagnosed with dementia. Other

care partners emphasized their roles in encouraging exercise and a healthy diet for OLWD as they grew older together.

### ***2.2 Preventing falls.***

This is the stage when care partners started to make efforts to prevent falls for OLWD. All the identified FRM behaviors were found to be relevant for this stage.

### ***2.3 Preparing to respond to falls.***

When older adults started to experience a high risk of falling, care partners began to put more effort into preparing to respond rapidly to older adults' fall incidents since they thought "they (OLWD) will fall no matter what I do - it is just a matter of time". In this stage, care partners focused on health and risk communication, improving older adults' help-seeking behaviors, enhancing safety supervision, adopting monitoring technology, and seeking informal support from families, friends, and neighbors. They also started to conduct more self-adjustment, such as reducing their work time and social or recreation activities, hoping to respond in a timely manner when OLWD fell.

### ***2.4 Responding to falls***

When older adults fell, care partners often needed to take immediate actions to assist older adults to stand and walk (if they were able to), assess and address the injuries that older adults experience, and make decisions about the services they need to utilize, such as emergency room visits or primary care appointments.

## **Discussion**

This study expands our knowledge of care partners' strategies to manage fall risk and fall incidents for community-dwelling OLWD and proposes a behavioral framework. These findings indicate that dementia care partners' FRM is a multi-domain and multi-stage process, which can be different possible mechanisms and processes through which

care partners can impact the fall risk among community-dwelling OLWD. Eight domains of dementia care partners' FRM behaviors were identified across four stages of FRM. These behaviors may be intentionally focused on FRM or unintentionally and differ across primary and secondary care partners.

### **Multi-domain Fall Risk Management Behaviors**

Our findings highlight the complexity of care partners' efforts in managing fall risk for community-dwelling OLWD similar to previous studies (Mcintyre & Reynolds, 2012; Meyer et al., 2016; Peach et al., 2017). Care partners play essential roles to ensure OLWD's access to necessary assistance, health information, behavioral change support, coordinated social and health services, environmental modifications, and care technologies. Comparing our findings with prior research (Zhou, Strayer, et al., 2020), this study reveals distinctive roles played by care partners that have not been identified or well-understood, including functional mobility assistance, assessing and addressing health conditions, learning behaviors, and communicating with other care partners and professionals.

Functional mobility assistance is viewed by care partners as vital to assist older adults with activities of daily living, such as toileting and shower/bath assistance. Previous studies suggest that OLWD without this assistance are at higher risk of nursing home placement and mortality (Gaugler et al., 2005). The study findings explain how care partners' care work in providing mobility and daily living assistance might reduce the risk of falling for community-dwelling OLWD. As this work is often undervalued and described as mundane care work (Seaman, 2018), future FRM interventions should incorporate support for care partners in providing this assistance to OLWD.



Hazard reminders are a specific type of assistance with functional mobility unique for OLWD. Care partners described how OLWD's cognitive and visuospatial impairment impacts how older adults perceived, analyzed, and interacted with the physical environment, especially outdoors. Thus, hazard reminders, such as reminding OLWD of uneven ground, are particularly important for older adults to stay mobile in the outdoors or other unfamiliar places, even if they still have good physical functions. When OLWD curtail going outside due to anxiety and fear, care partners' engagement in hazard reminders may be critical to ensure OLWD's ongoing engagement in outdoor activities (Brittain et al., 2010). This might contribute to the fall risk reduction and delayed adverse consequences of falls in addition to benefiting their well-being and quality of life (Gibson et al., 2007).

This study also revealed care partners' efforts in assessing OLWD's complex physical and mental health conditions. Previous studies suggested that care partners have limited insights on the risk and protective factors related to falls (Zhou, Strayer, et al., 2020). However, in this study, care partners often noticed that OLWD might be at risk of falls by observing their gait, balance, and concerning behaviors early on during their caring process. As fall risk assessment and management occur infrequently in primary care settings (Tinetti et al., 2006), the study findings reveal some opportunities to engage care partners to develop early detection and early response to fall risk among community-dwelling OLWD.

In addition to assessing OLWD's health conditions, care partners often provided mental and physical health care for OLWD, including managing, monitoring, and adjusting medication, implementing non-pharmacological interventions, as well as providing psychosocial support for OLWD. The AARP Special Report, *Home Alone*

*Revisited: Family Caregivers providing complex care* (Reinhard et al., 2019), suggested that today's caregivers provide more intense and complex care, including medical/nursing tasks and managing multiple health conditions. However, care partners often do not have sufficient medical or clinical training and supervision to carry out these tasks correctly/safely, which might be associated with a greater likelihood of acute care utilization for older adults and (Burgdorf et al., 2021), as well as care partners' emotional distress (Lee et al., 2019). Fall risk among OLWD is often associated with a variety of physical and mental health conditions of OLWD, requiring not only medical treatment as well as other non-pharmacological interventions, such as music therapy, physical therapy, occupation-centered activity, aromatherapy, and psychosocial support (Ebihara et al., 2021; Kim et al., 2017; Seaman, 2018). Therefore, engaging care partners in FRM requires training and support for care partners in adopting different approaches to address modifiable health conditions that contribute to the high risk of falling among OLWD, such as polypharmacy, urinary tract infections, diabetes, anxiety, depression, neuropsychiatric symptoms of dementia, sedentary behavior, and unmet needs (such as thirst, hunger, pain) (Casey et al., 2020).

This study also demonstrates how learning behaviors are fundamental for care partners to manage fall risk. Learning behaviors is a cognitive-behavioral process that care partners gain information, knowledge, and skills to address the needs of OLWD and themselves (Zhou, O'Hara, et al., 2020). The study shows that care partners learned about FRM not only from professional care providers, but also from their own life experiences of caring for others, other care partners, social networks, and the internet and media. This study finding also aligns with an earlier study that found that care partners learn how to manage fall risk for OLWD through "trial and error" from

interacting and learning from OLWD (Mcintyre & Reynolds, 2012), as well as drawing on a variety of learning resources (Meyer et al., 2016). There is currently limited evidence about specific successful strategies for enhancing the learning behaviors of dementia care partners (Zhou, O'Hara, et al., 2020). This study suggests that future FRM interventions should not view care partners as “empty vessels” (Meyer et al., 2016), but facilitate dementia care partners’ learning by integrating their life experiences, social networks, and interactions with different social and healthcare providers.

With diverse learning resources, care partners are not merely the recipients of knowledge and support from professional care providers. They also proactively call attention from other care partners and professional care providers to OLWD’s changing health and care needs and even share their perspective in health management for OLWD based on their experiences. Previous studies describe care partners as essential advocates for OLWD in healthcare settings (Sadak et al., 2016). This study found that care partners were also strong advocates for OLWD with home- and community-based services settings and with other care partners, calling their attention to OLWD’s needs for assistance regarding their high risk of falling. This finding demonstrates the distinctive and active role of care partners to improve current social and health services as they have lived experiences of where the gaps are.

### **Different Behavioral Partners of Primary and Secondary Care partners**

Another critical finding is the different behavioral patterns of primary and secondary care partners in FRM. Although having two or more care partners for OLWD is a common phenomenon (Gonçalves-Pereira et al., 2020; Koehly et al., 2015), few studies examine the similarities and differences between primary and secondary care

partners in FRM behaviors. According to our analysis, secondary care partners could also support OLWD's needs in health promotion, safety supervision, physical environment modifications, and accessing social and health care.

Previous studies have focused on examining challenges for multiple care partners providing support for the same OLWD. Primary care partners often encounter challenges to engaging secondary care partners (Tatangelo et al., 2018), while secondary care partners also face challenges to participate in care due to different challenges, especially for care partners working full time (Gonçalves-Pereira et al., 2020). Furthermore, secondary care partners may receive little guidance navigating their role (Gonçalves-Pereira, 2017). Primary and secondary care partners also may have different understandings, beliefs, and approaches in caring for OLWD, which can cause conflicts and communication breakdown among multiple care partners (Tatangelo et al., 2018). Fall prevention programs that support both primary and secondary care partners' health promotion support, safety supervision, physical environment modifications, and use of health and social services might be a feasible opportunity to facilitate collaborations and more effective care responsibility allocations among the care networks of OLWD.

### **Intentional and Unintentional Fall Risk Management Behaviors**

This study discovered care partners' FRM behaviors might be out of different intentions. Intentionally adopted behaviors for FRM might particularly be related to care partners' perceptions and knowledge of fall risk among OLWD. There might be different factors and mechanisms shaping care partners' unintentional FRM behaviors. Further exploration is needed to understand how to engage care partners to adopt these behaviors even if they might not have extensive knowledge and strong motivation to manage fall risk for OLWD. It provides an opportunity to develop FRM interventions to

build upon and reinforce care partners' existing care behaviors for other reasons, such as assessing and addressing health conditions, health promotion efforts, and receiving, seeking, and coordinating care. For example, providing additional training for care partners to identify and address risk and protective factors of OLWD's falls and fall-related injuries, or adding FRM programs into their current health promotion efforts or care planning process.

### **Multi-stage Process of Fall Risk Management**

Finally, this behavior framework highlights the complex trajectory of dementia care for care partners, especially the early engagement of care partners in health management for older adults before older adults were diagnosed with dementia. Such early involvement in health management for older adults is associated with better health outcomes and lower morbidity and mortality for older adults (Petrescu-Prahova et al., 2020).

A framework was proposed describing the trajectory of dementia caregiving from the early stage of dementia (Gallagher-Thompson et al., 2020). This approach revealed how dementia care challenges change over time; however, it does not include how care partners provide health management support to older adults before the onset and/or diagnosis of dementia and before they take on main care responsibilities. Care partners' early engagement in managing health and well-being, participating in healthcare activities, modifying the physical environment for older adults, and learning about caregiving might impact their efforts after their caring responsibilities increase as dementia progresses.

Furthermore, this framework suggests that care partners' FRM includes not only preventing falls but also preparing to respond appropriately to fall incidents. These

behaviors can help mitigate severe consequences after falling (Nguyen et al., 2018). This study found that care partners tried to educate OLWD about safe landing strategies and help-seeking after falls, techniques that are rarely incorporated into FRM interventions for OLWD (Moon & Sosnoff, 2017). Earlier studies found care partners also tried to provide immediate assistance when OLWD fell; however, they often did not receive training to do so without causing injuries to OLWD and to themselves (Davey et al., 2004). While personal injury is a known problem among nursing aides in residential settings, little attention has been given to the risk of injury among family care partners (Bulat et al., 2020). In this study, care partners often adopted more self-adjustment strategies when they felt the need to put more effort into detecting falls and preparing to rapidly respond to older adults' fall incidents. These self-adjustments, especially reducing working hours, self-care activities, and social activities might negatively impact care partners' health and well-being (Neubert et al., 2019; Rodakowski et al., 2012; Waligora et al., 2018). They also struggled to make decisions about using health services after falls, especially regarding emergency room visits (Leggett et al., 2018). These decisions affect not only OLWD and their care partners, but also may relate to emergency room visits and hospitalization (Jacobsohn et al., 2019). These results warrant the importance of preparing care partners to respond to OLWD's fall incidents to reduce the negative impact of OLWD's high risk of falling.

According to this study, at certain stages, care partners might perceive falls among OLWD as unavoidable, and therefore, focusing on preparations to respond to OLWD's fall incidents. Previous studies presented divergent perspectives on how to view care partners' fatalism. Some studies suggest the need to modify such perception since it may hinder care partners' efforts in FRM (Faes et al., 2010; Meyer et al., 2016). Another

study suggested that professional care providers need to understand how dementia care partners' risk management behaviors are sometimes based on fatalism and unpredictability to collaborate effectively with them (Buri & Dawson, 2000). Recently, there has been increased discussion about whether and when it is appropriate to shift focus from progressive fall risk prevention efforts to a more palliative approach. Such an approach considers falling a natural event at the end of life in some cases (Briggs & Wilson, 2021) and focuses on preserving or improving functional capacity with quality of life (Casey et al., 2020; Iaboni et al., 2018; Metzger et al., 2018).

### **Limitations**

This study has several limitations. First, the findings of this study were based on interviews with a small sample of dementia care partners in four counties in Washington State. The majority of participants were non-Hispanic white, 60 years and older, and spouses/partners and adult children. Therefore, the study findings might not capture experiences of dementia care partners who are from other racial/ethnic groups, care partners below 60 years old, or care partners who are friends or neighbors. Although some information about secondary care partners was collected and analyzed, it was reported by primary care partners. Future studies should further examine care partners' experiences in diverse contexts.

Another limitation relates to the analysis process. The author completed all the coding and analysis without a second coder, which might introduce bias in the analysis. This framework needs to be refined and validated among a larger sample size of diverse dementia care partners.

Finally, the framework was developed relying on qualitative research methods based on the content and meaning of these behaviors. It is not clear if care partners adopt multiple behaviors within each category of behavior simultaneously. For example, it is unclear if care partners who provide exercise supports are also providing diet support as both behaviors are health promotion support. If so, this framework can be used to guide the development of interventions that target FRM behaviors in the same category simultaneously, which is more practical and feasible for care partners and care providers to use this framework to inform their everyday practice. It is also not clear if those behaviors could significantly reduce fall risk reduction or mitigate the negative impact of fall risk on community-dwelling OLWD.

### **Conclusions and Implications**

The study was a first step to identifying different care partners' FRM behaviors to propose a multi-domain and multi-stage behavioral framework that could be applied to both primary and secondary care partners. The next steps for this work could include expanding and diversifying the sample, refining and validating the behavioral framework using quantitative data, and examining the associations between these behaviors and fall risk reduction.

This behavioral framework can be used to develop tools for social and health care providers to examine care partners' engagement in FRM, identify areas that need to be enhanced, and modify behaviors that might not be beneficial for OLWD, as well as mitigate the negative impact of these behaviors on care partners' own health and well-being. It is especially important to understand what factors might facilitate or hinder care partners' adoption of FRM behavior, such as OLWD's and care partners' health



conditions, training opportunities, or financial incentives provided by policymakers (Hoffman et al., 2017). Greater understanding is especially needed about understudied FRM behaviors, such as functional mobility assistance, assessing and addressing OLWD's physical and mental health conditions, learning behaviors, and communicating with other care partners and professionals. This understanding will inform the development of multi-domain and multi-stage interventions and policy efforts that target dementia care partners' FRM behaviors.

This study also revealed differences between primary and secondary care partners and intentional and unintentional FRM. Further studies should explore, compare, and integrate different strategies to engage primary and secondary care partners in FRM. Care providers also need to identify different approaches to collaborate with care partners who adopt FRM behaviors intentionally and unintentionally. Care providers also need to identify and respond to care partners' needs at different stages of FRM, especially before the dementia diagnosis and the advanced stage of dementia.

This study highlights the complexity of care partners' FRM that calls for attention from social and healthcare providers and policymakers to enhance the role of care partners in FRM. Acknowledging the contributions, limitations, and heterogeneity of dementia care partners may help address the substantial burden of falls among OLWD.

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## **PAPER TWO.**

### **VALIDATION OF A BEHAVIORAL FRAMEWORK FOR DEMENTIA CARE PARTNERS' FALL RISK MANAGEMENT**

#### **Introduction**

The risk of falls associated with dementia is a growing public health concern and social service challenge as it affects millions of older adults living with dementia (OLWD) and their care partners living in the community. OLWD have a two to ten times higher risk of falls compared to their age-matched peers without dementia (Allan et al., 2009). Although strong evidence gathered over 20 years supports the efficacy of specific fall prevention strategies for the general population of community-dwelling older adults, such as cataract surgery and exercises for strength and balance (Gillespie & Lamb, 2012), there is a lack of evidence for fall prevention strategies for community-dwelling OLWD (Peek et al., 2018). Furthermore, one study found that community-dwelling older adults living with “moderately severe dementia” are two to five times more likely to be members of Black/African American, Latinx, and immigrant communities and having less than a high school education (Harrison et al., 2019). This study also found that community-dwelling OLWD were also more likely than those in residential care to have more medical needs, such as more chronic illnesses, pain, falls in the last month, or fall concerns (Harrison et al., 2019). Given that this population is underserved and experiences a higher rate of falls, effective and feasible fall management interventions for community-dwelling OLWD are urgently needed.

Due to the progressive nature of dementia, care partners (partners/spouses, family, friends, neighbors, and other unpaid care partners) play essential roles in managing fall risk for these older adults. A recent systematic review showed that care

partners adopted multi-level strategies in managing fall risk (Zhou et al., 2020). They not only worked with OLWD directly managing their fall risk, but also adjusted their behaviors, modified the physical environment, and collaborated with other informal and formal care systems (Zhou et al., 2020). A recent study proposed a behavioral framework for dementia care partners' fall risk management (FRM), using a small sample of primary care partners who were non-Hispanic white and 60 years and older (Zhou, 2021). It identified 35 FRM behavioral items in eight domains, including (1) functional mobility assistance, (2) assessing and addressing health conditions, (3) health promotions support, (4) safety supervision, (5) physical environment modification, (6) receiving, seeking, and coordinating care, (7) learning, and (8) self-adjustment. However, this framework has not been evaluated using quantitative data. It is especially unclear how often these behaviors are adopted by dementia care partners at the population level. This information is critical to assess the overall efforts of care partners in FRM for community-dwelling OLWD, a population at high risk of falling.

The findings from this qualitative study (Zhou, 2021) suggest a multi-dimensional behavioral framework to assess and evaluate different care partners' FRM behaviors for community-dwelling OLWD. In the qualitative study, different FRM behaviors were categorized into eight domains based on the contents and meanings of these behaviors (Zhou, 2021). Previous research has not explored if those behaviors within each domain are adopted simultaneously; this gap might limit the usefulness of this framework to guide future research and interventions. If these behaviors are adopted in combination, examining single behaviors might be inadequate for taking into account the issue of collinearity among similar behaviors in the same domains. It is also possible that the effect of a single behavior may be too small to detect, but the

cumulative effects of multiple behaviors in one domain may be sufficiently large to be detectable. Therefore, it is important to examine the dimensionality of FRM behaviors. The dimensionality of FRM behavioral items represents the minimum number of latent variables that are needed to describe all statistical dependencies in the data (Barendse et al., 2015). Identifying the underlying structure of FRM behaviors will allow the evaluation of the cumulative impact of several FRM behaviors in the same domain on OLWD's fall-related outcomes. Studying the dimensionality of FRM can also have public health implications because it provides a more parsimonious framework that might be easier for the public to interpret and translate into care activities. It can also enhance our conceptual understanding of care partners' FRM behaviors and provide guidance for fall management interventions and education.

The proposed behavioral framework also highlights the different responsibilities of FRM between primary and secondary care partners. Previous studies suggested that when an OLWD has care support, they often have more than one care partner (Gonçalves-Pereira et al., 2020). Although all the care partners might contribute to care activities, there is typically one primary care partner (Fletcher, 2021; Ponnala et al., 2018). While primary care partners often adopted FRM behaviors from all these domains, secondary care partners also assisted with health promotion, safety supervision, physical environment modifications, and receiving, seeking, and coordinating care (Zhou, 2021). It is unclear if secondary care partners also engage in other types of FRM behaviors.

To my knowledge, no study has examined the adoption of these behaviors by care partners using quantitative data at the population level, or the variation in behavioral patterns between primary and secondary care partners (Zhou, 2021). This

proposed framework requires further validation in the following four aspects: (1) the prevalence of FRM behaviors; (2) how the prevalence of FRM behaviors differs between primary and secondary care partners, (3) the dimensionality of FRM behaviors based on how they are adopted simultaneously by dementia care partners; and (4) how the dimensionality of FRM behaviors differs between primary and secondary care partners.

Once validated, it is hoped that this framework can inform the development of clinical assessment, evaluation tools, and interventions that target different care partners, different domains of FRM, and different FRM behaviors. It can also be used by care partners to engage in FRM, as well as by social and healthcare service providers to identify potential opportunities to collaborate with dementia care partners in FRM.

## **Design and Methods**

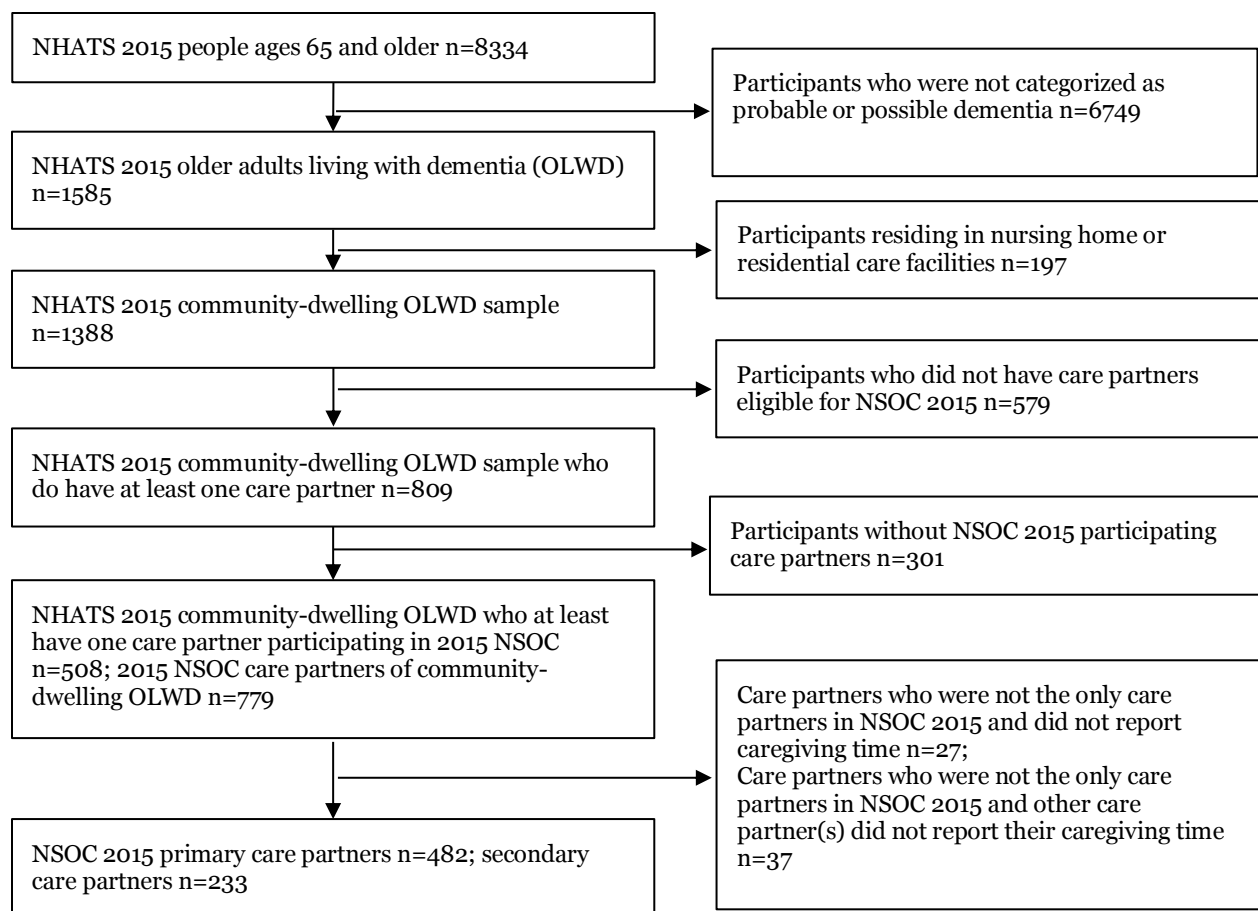
### **Study Population and Data Collection**

The study used data from the National Health and Aging Trends Study (NHATS) 2015 and National Study of Caregiving (NSOC) 2015, two linked national surveys that collect comprehensive information from older adults and their informal care partners. The NHATS is sponsored by the National Institute on Aging through a cooperative agreement with the Johns Hopkins Bloomberg School of Public Health. The NHATS was designed to follow successive nationally representative cohorts of people ages 65 and older and enrolled in Medicare, with an oversampling of non-Hispanic Blacks and those aged 85 and older using a stratified three-stage sampling design. NHATS participants undergo annual in-person interviews designed to collect detailed information on the disablement process and its consequences (Montaquila et al., 2012).

The NSOC is linked to NHATS. Respondents from the NHATS may identify up to

five individuals who provided them with assistance in personal care or household tasks (Kasper & Freedman, 2014; Wolff et al., 2016). Those caregivers are then administered a 30-minute telephone survey that includes questions on caregiving activities, duration and intensity of caregiving, support services sought and used, effects on caregiver's participation in activities including work, and personal and household demographics. NSOC has been conducted three times in conjunction with NHATS at period intervals (2011, 2015, 2017). NSOC 2011 and 2015 only provide cross-sectional descriptions about caregiving to older adults. NSOC 2017 includes both a cross-sectional sample and longitudinal follow-up with helpers identified in 2015. The current secondary data analysis using these data was deemed not human subjects research by the University of Washington institutional review board as all data were de-identified.

The analytic sample included 508 community-dwelling OLWD and their 779 care partners (See Figure 2.1). These 508 community-dwelling OLWD were identified through the dementia classification of their care recipients in the NHATS (Kasper et al., 2013). Data used to classify cognitive status included self- or proxy-report of medical provider-diagnosed dementia or Alzheimer's disease, the Eight-Item Interview to Differentiate Aging and Dementia screening questionnaire (Galvin et al., 2005), and clinical tests of memory, orientation, and executive functions. OLWD living in nursing homes and other residential settings were excluded. OLWD who did not have a care partner included in NSOC were also excluded from this study. Of the remaining sample, 170 OLWD had proxy assistance for survey items that they had difficulty responding to, typically due to health or memory problems. A proxy was someone familiar with the participants' health, daily routine, care arrangement, and preferably lived with the participants.



*Figure 2.1.* Diagram showing flow of participants included in the study.

For the final sample of 508 OLWD participants, 779 care partners were identified as part of the NSOC 2015. Of those, 482 were identified as primary care partners who spent the most time with OLWD or they were the only care partners participating in NSOC; other 233 care partners were identified as secondary care partners. Sixty-four care partners were not categorized due to one of the following occasions: (1) they were not the only care partner of OLWD and they did not report their caregiving time (n=27); or (2) they were not the only care partners of OLWD and other care partner(s) did not report their caregiving time (n=37). Not all care partners of OLWD participated in

NSOC, but an assumption of this categorization was that at least one of the care partners who participated in the NSOC were primary care partners.

## **Measures**

### **Characteristics of community-dwelling OLWD.**

The study reports three aspects of OLWD's characteristics from NHATS 2015.

(1) Sociodemographic characteristics include age, gender(male/female), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, and other race/ethnicity, including American Indian, Asian, Native Hawaiian, and multi-racial).

(2) Characteristics associated with receiving caregiving include the caregiving time received per week (hours), self-reported health status ("poor", "fair", "good", "very good", or "excellent"), number of chronic medical conditions (including heart attack, heart disease, hypertension, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia, and hip fracture), probable depression (if they scored 3 or above on the PHQ-2 scale, range 0-6) (Kroenke et al., 2009) and probable anxiety (if they scored 3 or above on the GAD-2 scale, range 0-6) (Löwe et al., 2008). These variables were selected because they might be associated with the risk of falling for OLWD (Casey et al., 2020) as well as their care partners' caregiving engagement (Stommel et al., 1995).

(3) Fall-related variables include fell down last month (yes/no), fell down in the last 12 months (yes/no), fell down more than one time in the last 12 months (yes/no), worried about falling down (yes/no) in the last month), worry about falling ever limited activities (yes/no). According to the fall risk literature among OLWD (Allan et al., 2009; Lach et al., 2017), selecting "yes" for variables mentioned above indicates higher fall risk. In the NHATS, falls were defined as "any fall, slip, or trip in which you lose your balance and land on the floor or ground or at a lower level".



### **Characteristics of dementia care partners.**

This study also reports relevant characteristics of care partners from NSOC, including sociodemographic characteristics: age, gender, marital status, race/ethnicity, education (high school degree/s, employment status (working/temporary not working/not working anymore). Other care partner characteristics included a mean number of hours of care provided per week, experiences of financial, emotional, and physical difficulty owing to caregiving; and health conditions that might interact with their care practices, including self-reported health, number of chronic medical conditions, as well as probable depression and anxiety. Health condition measures were the same as the measures used for OLWD. These health conditions are relevant to care partners' FRM for two reasons. First, prior research suggested that some care partners might expect to improve their health and well-being when engaging FRM for OLWD; for example, they might hope to improve their health when participating in an exercise fall management program designed for OLWD (Yao et al., 2008). Second, care partners' physical and mental health conditions might be associated with high demand for FRM. For example, OLWD's prior month falls was significantly associated with greater care-related emotional difficulty for care partners (Leggett et al., 2018); and care partners' participation in the fall management program for OLWD was significantly associated with decreased balance for care partners (Nyman et al., 2019). All these characteristics were described separately for primary and secondary care partners.

### **Care partners FRM behaviors.**

Based on the behavioral framework proposed in a previous study (Zhou, 2021), twenty-one FRM behaviors in seven domains were identified by matching the definitions of these behaviors and existing survey questions in NSOC 2015 (Appendix 2.1).

These FRM behaviors include the following domains:

- functional mobility assistance: stability support, weight support, and mobility support,
- assessing and addressing health conditions: medication management and wound care,
- physical environment modification: home safety modification and use of mobility device,
- health promotion support: diet support and exercise support,
- receiving, seeking, and coordinating care: use of paid care, use of informal care, use of respite care, making medical appointments, and medical communication,
- learning: use of support groups and receiving training, and
- self-adjustment: reducing family activities, reducing recreation activities, reducing religious activities, reducing group activities, and reducing work time.

One domain of FRM behaviors from the proposed framework, safety supervision, was not represented in NSOC. Other FRM behaviors, including mobility restraint, assessing OLWD's health conditions, ensuring the safety of shoes/socks, health and risk communication, enhancing activity engagement, improving and maintaining self-efficacy, improving help-seeking behaviors, learning from care partners' life experiences, OLWD, and media and internet, changing the living arrangement, changing the sleeping arrangement, and adapting walking arrangements, were also not represented in NSOC.

For FRM behavior variables operationalized in NSOC 2015, most of these variables were binary as they asked care partners if they adopted certain behaviors. “Refused” or “Don’t Know” responses were coded as “No”, assuming care partners who refused to answer these questions or reported “don’t know” are less likely to adopt these FRM behaviors. Only one variable (activity assistance) was originally an ordinal variable (how often did you help the older adult get around, 1 every day, 2 most days, 3 some days, 4, rarely, 5 never). For consistency in analysis, the variable was recoded into a binary variable (1-3 coded as 1, 4-5 coded as 0).

### **Data Analysis**

Analyses were conducted using STATA 15.0 (StataCorp, 2018) and R (R Core Team, 2013) using R package *mirt* (Chalmers, 2012).

#### **Descriptive statistics.**

First, I described the characteristics of community-dwelling OLWD using unweighted frequencies and weighted percentages to estimate the fall risk for the population of community-dwelling OLWD in the United States who have at least one care partner. I also described the characteristics and FRM behaviors of dementia care partners. The prevalence of FRM behaviors was estimated for the population of dementia care partners in the United States by their caring roles as either primary or secondary care partners after incorporating appropriate sampling weight. I present unweighted frequencies and weighted percentages as well as the results of weighted t-test and chi-square tests for differences between primary and secondary care partner groups. For all analyses, statistical significance was determined by  $\alpha < .05$  in a 2-sided hypothesis. All analyses used survey weights and design variables to account for complex, non-probability sampling and to produce nationally representative estimates; I

used Taylor series linearization incorporating the complex sample design to calculate variance estimates (95% confidence intervals [CI]) (Freedman et al., 2020). Three to six percentages of data were missing overall across all of the characteristic variables. No imputation was performed on missing items.

**Exploratory factor analysis (EFA) under item response theory (IRT).**

To examine the dimensionality of dementia care partners' FRM behaviors, I first used the NSOC 2015 care partner sample (N=779) and fitted an unconditional maximum likelihood EFA model under the multidimensional IRT paradigm followed by *oblimin* rotation. IRT is a model-based approach for specifying the functional relationship between a respondents' underlying latent trait level and an item level stimulus (Osteen, 2010). As FRM behavior variables are binary, factor analysis based on IRT is a suitable approach (van der Eijk & Rose, 2015). Because multiple domains of FRM had been suggested in prior research (Zhou, 2021), the multidimensional IRT, or MIRT, was chosen (Chalmers, 2012). MIRT is an extension of IRT and could be used to explore the underlying dimensionality of an IRT model (Osteen, 2010). Item parameters were estimated using the Metropolis-Hastings Robbins-Monro (MH-RM) method (Cai, 2010). The MH-RM algorithm allowed us to use stochastically imputed complete-data likelihood with an assumed population multivariate normal distribution, which is used to produce latent trait estimates and the imputed data (Chalmers, 2012). The *oblimin* rotation is used to the factor loading matrix to achieve a simpler loadings pattern and allow latent factors to correlate. R package *mirt* (Chalmers, 2012) provides estimated population parameters for the multidimensional model, which include factor loadings, communality, and factor covariances/correlations. When reading the loading matrix, a variable was loaded onto a factor when the load was greater than 0.4. When a variable

was loaded onto two factors when the load is greater than 0.4, it was removed from the model as it was a complex variable. If a variable could not be loaded on any factor when the load was greater than 0.4, it was removed as well.

The log-likelihood test and four information criteria were used for the identification of the number of factors to be extracted in EFA (Millsap et al., 2013). Unidimensional, two-, three-, four-, five-, six-, seven-, and eight-dimensional models were tested. The four information criteria were as follow: (a) the Akaike information criterion (AIC) (Akaike, 1974), (b) the corrected AIC (AICc) (Hurvich & Tsai, 1989), (c) the Bayesian information criterion (BIC) (Schwarz, 1978), and (d) the Sample-Size Adjusted BIC (SABIC) (Sclove, 1987). Lower values of the information indices indicate a better fit. The log-likelihood tests were conducted between nested models to find out whether a more complicated model fits better than the simple one (Ul Hassan & Miller, 2019).

For multidimensional item response models, when the number of items is large, or the number of respondents is small, traditional full-information information criteria cannot be trusted as the contingency table for possible response is sparse. Therefore, when four information criteria results and log-likelihood tests results were inconsistent, a limited-information method,  $M_2$  test statistic as well as associated indices root mean square error of approximation (RMSEA), SRMR (standardized root mean square residuals), comparative fit index (CFI), and the Tucker Lewis Index (TLI) that are based on  $M_2$  were used to evaluate model fit. The criteria were:  $p < 0.05$  were considered to show misfit; for the RMSEA and SRMR, values  $\leq 0.05$  ideal and values  $\leq 0.08$  were considered acceptable; for the CFI and TLI, values  $\geq 0.95$  ideal and  $\geq 0.90$  considered acceptable (Cai & Hansen, 2013).

If the chosen model required removal of any variables due to its factor loadings, the updated variable list was used to test unidimensional, two-, three-, four-, five-, six-, seven-, and eight-dimensional models, and compared these models based on full information and limited information methods. The iterative process continued until a model was tested having an ideal or acceptable fit and no variable needed to be removed. In the final model, each factor represents one unique domain of care partners' FRM behaviors. FRM behaviors having rotated absolute factor loading greater than or equal to 0.4 on a given factor were used to name the factor as different domains of FRM behaviors.

The associations among care partners who cared for the same care recipient might result in bias in the EFA. Therefore, the study repeated EFA analysis procedures described above on the primary care partner sample (n=482) and secondary care partner sample (n=233) separately. The final models from the analyses using subsamples were compared with each other and with the chosen model using the full sample.

EFA did not use survey weights. Prior work has suggested that IRT/EFA can be used for complex survey designs, while ignoring survey features and weights, in particular, can result in bias in item parameter point estimation. This study only used the IRT/EFA to explore the factor structure (Rol & Cyr, 2002; Wing et al., 2017).

## **Results**

### **Sample Description of Community-dwelling OLWD**

The characteristics of the 508 (weighted n= 3,890,352) community-dwelling OLWD are provided in Table 2.1. Their average age was 81.3 (95% CI: 80.3-82.3) (SD:

7.0). It was estimated that 56.6% (51.0%-62.1%) were female and 66.0% (61.0%-70.7%) were non-Hispanic white. OLWD received an average of 42.3 (37.0-47.6) hours of support per week.

Table 2.1. Characteristics of community-dwelling older adults living with dementia

|                                                                              | Mean (SD) or %           |
|------------------------------------------------------------------------------|--------------------------|
| <b>Age (n=508)<sup>a</sup></b>                                               | Mean: 81.3 (SD: 7.0)     |
| <b>Female (n=508)</b>                                                        | 323 (56.6%) <sup>b</sup> |
| <b>Race/ethnicity (n=506)</b>                                                |                          |
| Non-Hispanic White                                                           | 252 (66.0%)              |
| Non-Hispanic Black                                                           | 199 (19.6%)              |
| Hispanic                                                                     | 37 (8.6%)                |
| Other (American Indian/Asian/Native Hawaiian/Multi-racial)                   | 18 (5.9%)                |
| <b>Education (n=501)</b>                                                     |                          |
| <12 years                                                                    | 226 (37.8%)              |
| 12 years                                                                     | 143 (33.2%)              |
| >12 years                                                                    | 132 (29.0%)              |
| <b>Caregiving time received per week (hrs) (n=508)</b>                       | 42.3 (41.9)              |
| <b>Self-reported health fair or poor (n=508)</b>                             | 247 (49.7%)              |
| <b>Chronic medical conditions (n=497)</b>                                    | Mean: 3.2 (SD: 1.4)      |
| <b>Probable depression (n=495)</b>                                           | 141 (32.6%)              |
| <b>Probable anxiety (n=496)</b>                                              | 121 (27.4%)              |
| <b>Fall in the last month (n=508)</b>                                        | 96 (21.9%)               |
| <b>Fall in the last year (n=508)</b>                                         | 242 (52.2%)              |
| <b>Multiple fall last year (n=507)</b>                                       | 138 (30.7%)              |
| <b>Worried about falling (n=506)</b>                                         | 209 (44.3%)              |
| <b>Activity limitations due to worries about falling (n=506)<sup>c</sup></b> | 102 (23.0%)              |

Note:

- n represents the number of community-dwelling older adults living with dementia; total numbers may vary due to missing data. Among older adults whose responses were reported by proxy, 94 reported no worry, 74 reported worries; among those whose responses were reported by themselves, 203 reported no worry, 135 reported worries.
- Variance estimates (95%CI) of descriptive characteristics were not reported in the table but reported in the text.

About half of OLWD reported fair or poor health with an average of 3.2 (3.0-3.4, SD: 1.4) chronic medical conditions. Approximately one in three OLWD experienced probable depression (32.6%, 27.4%-38.2%) and probable anxiety (27.4%, 22.6%-32.8%). There were 21.9% (16.8%-28.0%) of OLWD experienced falls in the last month and 52.2% (46.7%-57.6%) of OLWD experienced falls in the last year. About 30.7% (25.7%-36.1%) of OLWD experienced multiple falls last year. There were 44.3% (38.9%-49.9%) of OLWD worried about falling and 23.0% (18.6%-28.0%) of them also experienced activity limitations due to their worry about falling.

### Sample Descriptions of Care Partners

Table 2.2. Characteristics of care partners of community-dwelling older adults living with dementia

|                                          | Individuals, Mean (SD)/No. (%) |                                              |                                                |                          |
|------------------------------------------|--------------------------------|----------------------------------------------|------------------------------------------------|--------------------------|
|                                          | <b>Total<br/>(N=779)</b>       | <b>Primary Care<br/>Partners<br/>(N=482)</b> | <b>Secondary Care<br/>Partners<br/>(N=233)</b> | <b>p-<br/>value</b>      |
| <b>Age (N<sup>a</sup>=761)</b>           | 57.6 (16.8)                    | 60.5 (15.8)                                  | 54.2 (16.3)                                    | <b>0.000<sup>b</sup></b> |
| <b>Female (N=776)</b>                    | 535 (64.3%) <sup>c</sup>       | 352 (68.6%)                                  | 141 (60.7%)                                    | 0.126                    |
| <b>Married (N=773)</b>                   | 438 (63.6%)                    | 271 (65.1%)                                  | 131 (57.2%)                                    | 0.131                    |
| <b>Race/ethnicity (N=763)</b>            |                                |                                              |                                                | 0.721                    |
| Non-Hispanic White                       | 359 (55.3%)                    | 228 (54.2%)                                  | 100 (50.2%)                                    |                          |
| Non-Hispanic Black                       | 290 (18.3%)                    | 172 (17.9%)                                  | 93 (20.4%)                                     |                          |
| Hispanic                                 | 66 (15.8%)                     | 43 (15.7%)                                   | 20 (19.1%)                                     |                          |
| Other <sup>d</sup>                       | 48 (10.6%)                     | 31 (12.3%)                                   | 14 (10.3%)                                     |                          |
| <b>Education (N=768)</b>                 |                                |                                              |                                                | 0.426                    |
| Highschool degree or less                | 329 (45.1%)                    | 199 (44.7%)                                  | 97 (41.3%)                                     |                          |
| Some college                             | 259 (32.9%)                    | 162 (33.9%)                                  | 79 (37.0%)                                     |                          |
| College degree                           | 110 (11.4%)                    | 75 (13.2%)                                   | 29 (9.8%)                                      |                          |
| Master's degree or higher                | 70 (10.6%)                     | 40 (8.2%)                                    | 24 (11.9%)                                     |                          |
| <b>Current employment status (N=772)</b> |                                |                                              |                                                | <b>0.040</b>             |
| Working                                  | 326 (45.6%)                    | 182 (39.7%)                                  | 117 (52.3%)                                    |                          |



Table 2.2. Continued.

|                                                     |                                |             |             |              |
|-----------------------------------------------------|--------------------------------|-------------|-------------|--------------|
| Temporary not working                               | 238 (28.8%)                    | 161 (30.3%) | 60 (27.7%)  |              |
| Retirement/No longer working/Unpaid work            | 208 (25.6%)                    | 137 (30.0%) | 52 (20.0%)  |              |
| <b>Hours of care per week/hrs (n=734)</b>           | 25.4 (41.0)<br>Range: 0.25-186 | 35.2 (49.0) | 10.3 (14.2) | <b>0.000</b> |
| <b>Relationship to care recipients (N=779)</b>      |                                |             |             | <b>0.000</b> |
| Spouse/partner                                      | 134 (19.1%)                    | 114 (29.2%) | 10 (4.0%)   |              |
| Adult children                                      | 476 (57.5%)                    | 283 (52.9%) | 153 (59.8%) |              |
| Others (other relatives, friends, others)           | 169 (23.4%)                    | 85 (17.9%)  | 70 (36.2%)  |              |
| <b>Financial difficulty (N=775)</b>                 | 175 (22.1%)                    | 121 (24.3%) | 45 (17.5%)  | 0.108        |
| <b>Emotional difficulty (N=774)</b>                 | 361 (49.6%)                    | 241 (50.5%) | 97 (45.9%)  | 0.399        |
| <b>Physical difficulty (N=775)</b>                  | 192 (23.5%)                    | 137 (26.6%) | 45 (22.1%)  | 0.343        |
| <b>Self-reported health fair or poor (N=772)</b>    | 173 (22.4%)                    | 110 (21.4%) | 47 (22.4%)  | 0.823        |
| <b>Number of chronic medical conditions (N=766)</b> | 3.5 (1.6)                      | 3.7 (1.7)   | 3.2 (1.5)   | <b>0.002</b> |
| <b>Probable depressive (N=760)</b>                  | 114 (17.5%)                    | 73 (18.0%)  | 32 (16.2%)  | 0.674        |
| <b>Probable anxiety (N=762)</b>                     | 110 (14.8%)                    | 76 (17.6%)  | 27 (11.5%)  | 0.108        |

*Note:*

- N represents the number of care partners of community-dwelling older adults living with dementia; total numbers may vary due to missing data.
- T-test and chi-square tests were weighted.
- Percentages were weighted.
- The other category includes American Indian/Asian/Native Hawaiian/Multi-racial.

Of 779 (weighted n=6,021,016) dementia care partners, characteristics of 482 primary care partners and 233 secondary care partners were reported (See Table 2.2). Primary care partners were on average older than secondary care partners (60.5 vs 54.2,  $p=0.000$ ). Primary care partners were less likely to be working (182 [39.7%] vs. 97 [52.3%],  $p=0.040$ ), provide more hours of care per week (35.2 vs 10.3,  $p=0.000$ ), and have more chronic medical chronic conditions (3.7 vs 3.2,  $p=0.002$ ). For primary and secondary care partners, the highest degree of more than 40% of them was a high school

degree or less, and more than half of them were adult child partners. Primary care partners were more often a spouse/partner (114 [29.2%] vs 10 [4%],  $p=0.000$ ). The majority of care partners were female (64.3% overall; primary care partners: 68.6%; secondary care partners: 60.7%). There were also no significant differences in terms of marital status, race/ethnicity, financial/emotional/ physical difficulty, self-reported health, and depression symptoms. Although higher percentages of primary care partners (17.6%) had probable anxiety compared to secondary care partners (11.5%), the differences were not statistically significant.

### **Prevalence of FRM Behaviors and Differences between Primary and Secondary Care Partners**

In 2015, about half of all care partners provided functional mobility assistance and physical environment modification (See Table 2.3). Although 62.4% (95% CI: 57.2%-67.3%) of care partners helped OLWD with medication management, only 27.8% (23.4%-32.6%) assisted with wound care. About one in three care partners provided health promotion support, including diet support (30.8%, 26.1%-36.0%) and exercise support (36.9%, 31.7%-42.3%). Fewer care partners adopted learning behaviors from support groups (3.4%, 2.0%-5.8%) or received training to take care of OLWD (8.1%, 5.5%-11.8%). About 10%-20% of care partners adopted self-adjustment behaviors. The prevalence of receiving, seeking, and coordinating care behaviors varied: 71.6% (66.7%-76.0%) of care partners used other informal care for OLWD, while only 21.9% (18.4%-25.9%) used paid care, with 18.5% (15.2%-22.3%) using respite care. More than half helped with accessing medical services, including making medical appointments 67.9% (62.9%-72.5%) and communicating with medical providers for OLWD 56.0% (50.8%-61.1%).

Table 2.3. Prevalence of FRM behaviors among primary and secondary care partners (CP) based on proposed framework

| Individuals, No. (%)                               |                                |                          |                            |                           |
|----------------------------------------------------|--------------------------------|--------------------------|----------------------------|---------------------------|
|                                                    | Total<br>(N=779 <sup>a</sup> ) | Primary<br>CP<br>(N=482) | Secondary<br>CP<br>(N=233) | p-value                   |
| Domain 1: Functional mobility assistance           |                                |                          |                            |                           |
| 1.1 Stability support                              | 453 (54.4%) <sup>b</sup>       | 282 (54.4%)              | 140 (57.9%)                | 0.514                     |
| 1.2 Weight support                                 | 455 (56.4%)                    | 285 (55.9%)              | 141 (58.9%)                | 0.579                     |
| 1.3 Mobility support                               | 466 (57.4%)                    | 297 (56.9%)              | 142 (56.9%)                | 0.998                     |
| Domain 2: Assess and address health conditions     |                                |                          |                            |                           |
| 2.1 Medication management                          | 540 (62.4%)                    | 373 (72.3%)              | 129 (41.5%)                | <b>0.000</b> <sup>c</sup> |
| 2.3 Wound care                                     | 228 (27.8%)                    | 160 (31.5%)              | 58 (21.9%)                 | <b>0.031</b>              |
| Domain 3: Physical environment modification        |                                |                          |                            |                           |
| 3.1 Home safety modification                       | 381 (44.4%)                    | 247 (49.1%)              | 113 (44.6%)                | 0.390                     |
| 3.2 Use of mobility devices                        | 406 (50.4%)                    | 257 (53.2%)              | 123 (53.8%)                | 0.904                     |
| Domain 4: Health promotion support                 |                                |                          |                            |                           |
| 4.1 Diet support                                   | 251 (30.8%)                    | 176 (35.0%)              | 57 (20.5%)                 | <b>0.002</b>              |
| 4.2 Exercise support                               | 286 (36.9%)                    | 188 (38.1%)              | 83 (30.0%)                 | 0.098                     |
| Domain 5: Receiving, seeking and coordinating care |                                |                          |                            |                           |
| 5.1 Use of paid care                               | 201 (21.9%)                    | 125 (23.5%)              | 54 (21.6%)                 | 0.642                     |
| 5.2 Use of informal care                           | 566 (71.6%)                    | 313 (62.6%)              | 200 (81.3%)                | <b>0.001</b>              |
| 5.3 Use of respite care                            | 163 (18.5%)                    | 110 (21.2%)              | 43 (17.1%)                 | 0.309                     |
| 5.4 Making medical appointments                    | 559 (67.9%)                    | 394 (76.9%)              | 123 (46.4%)                | <b>0.000</b>              |
| 5.5 Medical communication                          | 461 (56.0%)                    | 330 (64.8%)              | 101 (36.1%)                | <b>0.000</b>              |
| Domain 6: Learning                                 |                                |                          |                            |                           |
| 6.1 Use of support group                           | 35 (3.4%)                      | 26 (4.5%)                | 8 (2.4%)                   | 0.273                     |
| 6.2 Receiving training                             | 71 (8.1%)                      | 49 (10.8%)               | 19 (5.5%)                  | 0.065                     |
| Domain 7: Self-adjustment                          |                                |                          |                            |                           |
| 7.1 Reducing family activities                     | 184 (17.3%)                    | 131 (20.8%)              | 44 (13.5%)                 | <b>0.034</b>              |
| 7.2 Reducing recreation activities                 | 155 (17.1%)                    | 112 (21.3%)              | 38 (13.8%)                 | <b>0.049</b>              |
| 7.3 Reducing religious activities                  | 116 (13.9%)                    | 91 (18.7%)               | 22 (8.7%)                  | <b>0.008</b>              |
| 7.4 Reducing group activities                      | 99 (11.2%)                     | 74 (14.0%)               | 21 (8.7%)                  | 0.115                     |

Table 2.3. Continued.

|                        |           |            |           |       |
|------------------------|-----------|------------|-----------|-------|
| 7.5 Reducing work time | 88 (9.5%) | 63 (11.8%) | 21 (8.2%) | 0.240 |
|------------------------|-----------|------------|-----------|-------|

*Note:*

- a. Data are from the 2015 National Study of Caregiving (unweighted sample for total sample, n=779, weighted sample: 6,021,016).
- b. Percentages are weighted; variance estimates (95%CI) of descriptive characteristics were not reported in the table but reported in the text.
- c. Bolded p value >p.05.

### **Differences in Prevalence of FRMB between Primary and Secondary Care Partners**

Compared to secondary care partners, primary care partners were more likely to help with medication management (primary: 373 [72.3%] vs secondary: 129 [41.5%],  $p=0.000$ ) and wound care (160 [31.5%] vs 58 [21.9%],  $p=0.031$ ), diet support (176 [35.0%] vs 57 [20.5%],  $p=0.002$ ), making medical appointments (394 [76.9%] vs 123 [46.4%],  $p=0.000$ ) and medical communication (330 [64.8%] vs 101 [36.1%],  $p=0.000$ ). Secondary care partners were more likely to use other informal care for OLWD (313 [62.6%] vs 200 [81.3%],  $p=0.001$ ). Primary care partners were more likely to make adjustments to their other routine activities, such as reducing their family activities (131 [20.8%] vs 44 [13.5%],  $p=0.034$ ), reducing recreational activities (112 [21.3%] vs 38 [13.8%],  $p=0.049$ ), reducing religious activities (91 [18.7%] vs 21 [8.7%],  $p=0.008$ ), reducing group activities (74 [14.0%] vs 21 [8.7%],  $p=0.115$ ), and reducing work times (63 [11.8%] vs. 21 [8.2%],  $p=0.240$ ), although the differences for the last two behaviors were not significant. There were no significant differences between primary and secondary care partners on other FRM behaviors.

## The Dimensionality of Dementia Care Partners' FRM Behaviors

Table 2.4. Factor structure and factor correlations for care partners' fall risk management (FRM) behaviors <sup>a</sup>

|                                    | F1 <sup>b</sup>           | F2            | F3                    | F4            | F5            | F6            | F7           | Communality        |
|------------------------------------|---------------------------|---------------|-----------------------|---------------|---------------|---------------|--------------|--------------------|
| 1.1 Stability support              | <b>-0.928<sup>c</sup></b> | 0.024         | -0.003                | -0.010        | 0.025         | -0.055        | 0.022        | 0.840 <sup>d</sup> |
| 1.2 Weight support                 | <b>-0.878</b>             | 0.007         | 0.031                 | 0.004         | -0.013        | 0.054         | 0.019        | 0.809              |
| 1.3 Activity support               | <b>-0.617</b>             | -0.172        | -0.086                | -0.073        | -0.073        | -0.096        | 0.059        | 0.648              |
| 2.1 Diet support                   | -0.178                    | <b>-0.584</b> | 0.041                 | 0.070         | 0.049         | 0.005         | 0.053        | 0.636              |
| 2.2 Exercise support               | 0.036                     | <b>-0.797</b> | -0.020                | -0.106        | -0.123        | -0.002        | 0.029        | 0.635              |
| 3.1 Making medical appointments    | -0.008                    | 0.025         | <b>0.926</b>          | 0.016         | 0.061         | -0.014        | 0.045        | 0.871              |
| 3.2 Medical communication          | 0.015                     | -0.054        | <b>0.840</b>          | -0.060        | -0.091        | -0.005        | -0.016       | 0.769              |
| 4.1 Use of paid care               | -0.054                    | -0.043        | -0.009                | <b>-0.778</b> | 0.130         | -0.124        | -0.065       | 0.635              |
| 4.2 Use of respite care            | 0.003                     | 0.055         | 0.064                 | <b>-0.832</b> | -0.112        | 0.089         | 0.064        | 0.771              |
| 5.1 Receiving training             | -0.112                    | -0.032        | 0.095                 | 0.047         | <b>-0.622</b> | -0.085        | -0.102       | 0.633              |
| 5.2 Use of support group           | 0.135                     | 0.037         | -0.101                | 0.139         | <b>-0.757</b> | 0.003         | 0.230        | 0.513              |
| 6.1 Home safety modification       | 0.057                     | -0.237        | 0.003                 | -0.219        | -0.025        | <b>-0.524</b> | 0.023        | 0.537              |
| 6.2 Use of mobility devices        | -0.027                    | 0.043         | 0.028                 | 0.035         | -0.028        | <b>-0.896</b> | 0.035        | 0.824              |
| 7.1 Reducing family activities     | -0.025                    | 0.016         | 0.004                 | -0.018        | 0.1010        | 0.003         | <b>0.914</b> | 0.819              |
| 7.2 Reducing recreation activities | 0.026                     | -0.020        | -0.024                | 0.010         | -0.044        | -0.008        | <b>0.930</b> | 0.867              |
| 7.3 Reducing religious activities  | 0.050                     | 0.001         | 0.068                 | 0.010         | -0.030        | 0.010         | <b>0.807</b> | 0.670              |
| 7.4 Reducing group activities      | -0.094                    | -0.043        | 0.031                 | 0.000         | -0.030        | -0.042        | <b>0.821</b> | 0.832              |
| 7.5 Reducing work time             | -0.112                    | 0.044         | 0.018                 | -0.008        | -0.024        | -0.047        | <b>0.592</b> | 0.486              |
| <b>M<sub>2</sub> test</b>          | <b>df</b>                 | <b>p</b>      | <b>RMSEA (0.9 CI)</b> |               | <b>SRMSR</b>  | <b>TLI</b>    | <b>CFI</b>   |                    |
| 63.760                             | 87                        | 0.063         | 0.021 (0-0.033)       |               | 0.021         | 0.989         | 0.996        |                    |

Note:

- Use of informal care, wound care, and medication management were not included in the model. EFA performed on 18 FRM behaviors.
- F1 functional mobility assistance, F2 health promotion support, F3 accessing medical care, F4 accessing formal social care, F5 learning, F6 physical environmental modification, and F7 self-adjustment.
- Loadings' absolute value  $\geq 0.4$  defined the domains of FRM behaviors and were shown in bold typeface.

- d. The magnitude of each loading measures the importance of the corresponding behaviors to the latent traits that suggest different domains of FRM behaviors. Communality measures the proportion of the variance of each FRM behavior variable explained by the numbers of factors in each model.

Based on the iterative EFA process, the use of informal care, wound care, and medication management were removed from the model and the seven-dimensional model was chosen based on the four information criteria and  $M_2$  test (Appendix 2.2). Medication management was a complex variable as it had a loading of 0.4 or higher on two factors (the factor of diet support and exercise support, and the factor of making medical appointments and medical communication). The use of informal care and wound care were not loaded onto any factor or with complex variables. The seven-dimensional model had the smaller AIC, significant log-likelihood test results ( $p=0.000$ ) and showed ideal fit in the  $M_2$  test:  $M_2^*(2) = 63.76$ ,  $p=0.063$ ,  $RMSEA = 0.021$  (90% CI: 0-0.033),  $SRMSR=0.021$ ,  $TLI=0.989 > 0.95$ ,  $CFI=0.996 > 0.95$ .

Table 2.4 displays the rotated factor loadings. FRM behaviors having rotated absolute factor loading greater than or equal to 0.4 on a given factor and the definition of each behavior (Zhou, 2021) were used to identify concepts to name the factor as different domains of FRM behaviors. The analysis generated seven interpretable domains regarding care partners' FRM behaviors:

- functional mobility assistance: stability support, weight support, and activity support,
- health promotion support: diet support and exercise support,
- accessing medical care: making medical appointments and medical communication,
- accessing formal social care: use of paid care and use of respite care,
- learning: receiving training and use of support group,

- physical environment modification: home safety modification and use of mobility devices, and
- self-adjustment: reducing family activities, reducing recreation activities, religious activities, group activities, and working time.

The two new constructs identified are: 1. accessing medical care, defined as care partners utilize medical care, receive, and ask for help from healthcare providers for OLWD; and 2. accessing formal social care, defined as care partners utilizing paid social care to provide support for OLWD when they are not available or need to take a break.

### **Differences in the dimensionality of FRM Behaviors between Primary and Secondary Care Partners**

EFA analysis procedures were repeated on the sub-samples of primary and secondary care partners. The full-information and limited information methods were used to determine the number of dimensions (Appendix 2.3).

For primary care partners, the six-dimensional model, which omitted the use of informal care, wound care, medication management, and learning behaviors, was chosen based on the iterative EFA process. Primary care partners' learning behaviors (use of support groups and receiving training), use of informal care, and wound care were removed as they did not have 0.4 or higher loading on any factor. Medicament management was removed as it was a complex variable. After removing these five behaviors, the factor structure of the finalized model for primary care partners was similar to the factor structure generated using the full sample (Table 2.5).

For secondary care partners, the four-dimension model, which omitted the use of informal care, wound care, and diet support was the best fit for the subsample of secondary care partners. After removing these three variables as they did not have 0.4 or

higher loading on any factor, all the FRM behaviors of secondary care partners were grouped into four clusters (See in Table 2.6): 1. functional mobility assistance; 2. accessing medical services and medication management; 3. exercise support, physical environmental modification, accessing formal social services, and receiving training; and 4. self-adjustment and use of support groups.

Table 2.5. Factor structure of FRM behaviors among primary care partners <sup>a</sup>

|                                    | <b>F1<sup>b</sup></b>    | <b>F2</b>     | <b>F3</b>         | <b>F4</b>       | <b>F5</b>     | <b>F6</b>         | <b>Communi-<br/>-nality</b> |
|------------------------------------|--------------------------|---------------|-------------------|-----------------|---------------|-------------------|-----------------------------|
| 1.1 Stability support              | <b>0.886<sup>c</sup></b> | -0.050        | 0.029             | 0.047           | -0.009        | 0.052             | 0.790 <sup>d</sup>          |
| 1.2 Weight support                 | <b>0.920</b>             | 0.061         | 0.015             | -0.047          | 0.026         | -0.084            | 0.837                       |
| 1.3 Activity support               | <b>0.688</b>             | -0.102        | -0.148            | 0.028           | -0.060        | 0.013             | 0.669                       |
| 2.1 Home safety modification       | -0.030                   | <b>-0.666</b> | -0.128            | -0.024          | -0.137        | -0.025            | 0.557                       |
| 2.2 Use of mobility devices        | 0.114                    | <b>-0.709</b> | 0.089             | 0.039           | 0.038         | -0.091            | 0.597                       |
| 3.1 Diet support                   | -0.024                   | 0.013         | <b>-0.853</b>     | -0.007          | 0.063         | -0.065            | 0.741                       |
| 3.2 Exercise support               | 0.256                    | -0.035        | <b>-0.523</b>     | 0.071           | -0.139        | 0.026             | 0.505                       |
| 4.1 Making medical appointment     | 0.016                    | 0.007         | 0.068             | <b>0.832</b>    | 0.049         | -0.075            | 0.721                       |
| 4.2 Medical communication          | -0.011                   | 0.007         | -0.051            | <b>0.943</b>    | -0.047        | 0.037             | 0.886                       |
| 5.1 Use of paid care               | 0.031                    | -0.132        | -0.075            | -0.059          | <b>-0.726</b> | 0.033             | 0.587                       |
| 5.2 Use of respite care            | -0.012                   | 0.051         | 0.075             | 0.057           | <b>-0.872</b> | -0.060            | 0.791                       |
| 6.1 Reducing family activities     | 0.029                    | 0.155         | -0.004            | -0.060          | -0.072        | <b>-0.957</b>     | 0.884                       |
| 6.2 Reducing recreation activities | -0.040                   | -0.093        | -0.021            | 0.039           | -0.002        | <b>-0.863</b>     | 0.811                       |
| 6.3 Reducing religious activities  | -0.044                   | -0.093        | 0.013             | 0.072           | 0.025         | <b>-0.752</b>     | 0.613                       |
| 6.4 Reducing group activities      | 0.062                    | -0.106        | -0.045            | 0.043           | 0.031         | -<br><b>0.828</b> | 0.843                       |
| 6.5 Reducing work time             | 0.113                    | -0.089        | -0.053            | 0.029           | -0.007        | <b>-0.529</b>     | 0.428                       |
| <b>M<sub>2</sub> test</b>          | <b>df</b>                | <b>p</b>      | <b>RMSE<br/>A</b> | <b>(0.9 CI)</b> | <b>SRMSR</b>  | <b>TLI</b>        | <b>CFI</b>                  |
| 35.362                             | 39                       | 0.637         | 0                 | 0-0.027         | 0.027         | 1.004             | 1                           |

Note:

- a. For primary care partners, use of informal care, wound care, medication management, and learning (including use of support groups and receiving training) were removed for generating this model.



- b. F1 functional mobility assistance, F2 physical environmental modification, F3 health promotion support, F4 accessing medical care, F5 accessing formal social care, and F6 self-adjustment.
- c. Loadings' absolute value  $\geq 0.4$  defined the domains of FRM behaviors and were shown in bold typeface. The magnitude of each loading measures the importance of the corresponding behaviors to the latent traits that suggest different domains of FRM behaviors.
- d. Communality measures the proportion of the variance of each FRM behavior variable explained by the numbers of factors in each model.

For secondary care partners, the four-dimension model, which omitted the use of informal care, wound care, and diet support was the best fit for the subsample of secondary care partners. After removing these three variables as they did not have 0.4 or higher loading on any factor, all the FRM behaviors of secondary care partners were grouped into four clusters (See in Table 2.6): 1. functional mobility assistance; 2. accessing medical services and medication management; 3. exercise support, physical environmental modification, accessing formal social services, and receiving training; and 4. self-adjustment and use of support groups.

Table 2.6. Factor structure of FRM behaviors among secondary care partners <sup>a</sup>

|                                | F1 <sup>b</sup>           | F2           | F3            | F4     | Communi-<br>-nality |
|--------------------------------|---------------------------|--------------|---------------|--------|---------------------|
| 1.1 Stability support          | <b>0.895</b> <sup>c</sup> | -0.057       | -0.011        | 0.039  | 0.824 <sup>d</sup>  |
| 1.2 Weight support             | <b>0.934</b>              | 0.037        | 0.009         | 0.050  | 0.902               |
| 1.3 Activity support           | <b>0.529</b>              | -0.160       | -0.377        | 0.113  | 0.584               |
| 2.1 Medication management      | -0.035                    | <b>0.409</b> | -0.247        | 0.314  | 0.431               |
| 2.2 Making medical appointment | -0.044                    | <b>0.949</b> | 0.025         | 0.042  | 0.895               |
| 2.3 Medical communication      | 0.002                     | <b>0.781</b> | -0.090        | 0.002  | 0.649               |
| 3.1 Home safety modification   | 0.132                     | 0.101        | <b>-0.752</b> | -0.096 | 0.657               |
| 3.2 Use of mobility devices    | 0.262                     | 0.137        | <b>-0.523</b> | -0.174 | 0.442               |
| 3.3 Exercise support           | 0.146                     | -0.075       | <b>-0.597</b> | 0.261  | 0.572               |
| 3.4 Use of paid care           | 0.005                     | 0.026        | <b>-0.652</b> | -0.200 | 0.413               |
| 3.5 Use of respite care        | -0.140                    | 0.075        | <b>-0.718</b> | 0.098  | 0.533               |
| 3.6 Receiving training         | -0.136                    | -0.106       | <b>-0.485</b> | 0.305  | 0.331               |

Table 2.6. continued.

| 4.1 Use of support group           | -0.246 | -0.213 | -0.116        | <b>0.799</b> | 0.615 |     |
|------------------------------------|--------|--------|---------------|--------------|-------|-----|
| 4.2 Reducing family activities     | 0.040  | 0.096  | -0.083        | <b>0.825</b> | 0.779 |     |
| 4.3 Reducing recreation activities | 0.042  | 0.049  | 0.059         | <b>0.980</b> | 0.980 |     |
| 4.4 Reducing religious activities  | 0.118  | 0.010  | 0.156         | <b>0.868</b> | 0.782 |     |
| 4.5 Reducing group activities      | 0.151  | 0.134  | -0.059        | <b>0.766</b> | 0.769 |     |
| 4.6 Reducing work time             | 0.216  | 0.112  | -0.212        | <b>0.509</b> | 0.542 |     |
| M <sub>2</sub> test                | df     | p      | RMSEA (90%CI) | SRMSR        | TLI   | CFI |
| 72.248                             | 73     | 0.503  | 0(0-0.037)    | 0.039        | 1.002 | 1   |

Note:

- For secondary care partners, use of informal care, wound care, and diet support were removed for generating this model.
- F1 functional mobility assistance, F2 accessing medical services and medication management, F3 exercise support, physical environmental modification, accessing formal social services, and receiving training, and F4 self-adjustment and use of support groups
- Loadings' absolute value  $\geq 0.4$  defined the domains of FRM behaviors and were shown in bold typeface. The magnitude of each loading measures the importance of the corresponding behaviors to the latent traits that suggest different domains of FRM behaviors.
- Communality measures the proportion of the variance of each FRM behavior variable explained by the numbers of factors in each model.

## Discussion

This study provides the first national profile of care partners' engagement in FRM for community-dwelling OLWD. The findings first described the prevalence of falls and fall-related outcomes for community-dwelling OLWD who had at least one care partner. The study highlights the high prevalence of falls, recurrent falls, and worry about falling among this population. More than half of these community-dwelling OLWD fell in the last year and one in three of OLWD fell multiple times in the last year. More than 44% reported worry about falling and half of these OLWD experienced activity limitations associated with worry about falling. These findings underscore the need to support OLWD and their care partners to manage fall risk at home. Reducing falls would mean reductions in morbidity, mortality, and healthcare expenditure associated with falls

(Burns et al., 2016; Peek et al., 2018), as well as delayed declines in well-being, quality of life, independence, and increased care burden associated with worry about falling, and associated activity limitations (Denkinger et al., 2015; Kamiya et al., 2014; Leggett et al., 2018).

The study showed that the majority of both primary and secondary care partners were women, married, and adult children of OLWD. The finding confirms the pivotal role of women in providing care for OLWD living in the community, and points attention to the growing involvement of adult children in providing care and support for OLWD in the United States (Alzheimer's Association, 2021). It suggests the increasing need to support adult children to navigate their unique challenges caring for OLWD, such as balancing care with work and other care responsibilities (Gonçalves-Pereira et al., 2020). Relative to secondary care partners, primary care partners were older, less formally educated, more likely to be the spouse of OLWD, and less likely to work at full-time or part-time jobs, which aligned with a prior study about the characteristics of primary and secondary care partners (Gaugler et al., 2003). This study confirmed these different characteristics of primary and secondary care partners at the population level in the United States. Different strategies to engage primary and secondary care partners in FRM are needed considering their diverse age, education, employment, and caring relationships with OLWD.

Although assessing differences between primary and secondary care partners' health conditions was not the main objective of the study, it is noticeable that no significant differences were detected between these groups regarding caregiving difficulty, self-reported health, probable depression, and probable anxiety. However, the study found that primary care partners might experience more chronic conditions than

do secondary care partners. Prior studies found primary care partners had high subjective burden (Bédard et al., 2001; Gonçalves-Pereira et al., 2020), but do not differ from secondary partners in terms of positive aspects of caregiving, psychological distress, or self-report health (Gaugler et al., 2003; Gonçalves-Pereira et al., 2020). Our studies confirmed the need to further understand the how caring for OLWD impact secondary care partners rather than assuming that their task is too easy to have a measurable impact on them (Gonçalves-Pereira et al., 2020). Prior studies have not examined the differences in physical health between primary and secondary care partners (Gaugler et al., 2003; Gonçalves-Pereira et al., 2020; Marino et al., 2020). Primary care partners' higher number of chronic conditions might be related to their older age compared to secondary care partners. Both advanced age and higher number of chronic conditions are associated with risk of falling for older adults (Ambrose et al., 2013; Immonen et al., 2020). Considering the higher risk of falling among care partners of older adults (Bouldin et al., 2019), engaging care partners to manage fall risk for community-dwelling OLWD might also provide an opportunity for care partners to address their risk of falling.

### **Prevalence of FRM Behaviors**

It is important to understand how common FRM behaviors are to inform interventions and services for care partners of community-dwelling OLWD. In this nationally representative sample of dementia care partners, the most commonly adopted FRM behaviors were functional mobility assistance and physical environment modification, ranging from 44.4%-57.4%. Health promotion support had moderate prevalence (30.8%-36.9%). Learning and self-adjustment were the least prevalent, ranging from 3.4%-17.3%.

Assessing and addressing health conditions and receiving, seeking, and coordinating care had varied prevalence. Medication management was highly prevalent (62.4%), but wound care was less prevalent (27.8%). Behaviors related to medical care were highly prevalent, ranging from 56.0%-67.9%. Use of informal care was highly prevalent (71.6%) but accessing formal social care was less prevalent (18.5%-21.9%).

These findings suggest different opportunities for intervention development to engage dementia care partners. The high prevalence of certain FRM behaviors, such as medication management, functional mobility assistance, and physical environment modification, suggests that a significant proportion of dementia care partners may benefit from (and possibly be drawn to) interventions targeting those FRM behaviors, such as opportunities to learn about medication management to prevent falls (Gray et al., 2021). The low prevalence of formal social service use may be attributed to the unique challenges OLWD and their care partners face in accessing formal social services (Feldman et al., 2021), such as lacking awareness of available services, difficulties in obtaining information about services, psychological barriers to utilizing resources, or insufficient resources provided in the community (Røsvik et al., 2020). A prior study has suggested that having a formal caregiver was significantly associated with risk reduction for fall-related injury for community-dwelling OLWD (Hoffman et al., 2016); however, to my knowledge, there were no studies examining the impact of using other social services, such as the use of respite care, on fall risk reduction. This indicates a need for research that examines the impact of different types of formal social services on fall risk reduction, as well as facilitators and barriers for care partners to collaborate with formal social care systems in FRM.

This study found that specific behaviors that are known to support FRM, such as diet support, exercise support, and learning, have only low-to-moderate prevalence. Prior studies highlighted the potential benefits of nutrition guidance programs (Suominen et al., 2015) and exercise programs (Pitkälä et al., 2013) in fall risk reduction. The low-to-moderate prevalence of these behaviors warrants the need to develop relevant interventions to improve the care partners' uptake of these behaviors.

### **How the Prevalence of FRM Behaviors Differs between Primary and Secondary Care Partners**

According to the present study, compared with secondary care partners, primary care partners provide more types of instrumental activities of daily living, such as diet support, medication, wound care, and accessing medical services for OLWD. Primary care partners are also more likely to make adjustments to their own routine activities, which might have a negative impact on their health and well-being (Waligora et al., 2018). This finding suggests the need to address primary care partners' need for self-care when engaging them in FRM. Despite the differences, secondary care partners still provide substantial support in medication management (45.7%), making medical appointments (50.9%), and medical communication (39.1%).

This study revealed that there were no significant differences between primary and secondary care partners in some types of FRM behaviors, including functional mobility assistance, physical environment modification, learning, and accessing formal social care, which aligned with the findings from a qualitative examination of these behaviors (Zhou, 2021).

The differences between primary and secondary care partners highlight the critical role of primary care partners in FRM, especially in diet support and medical care

tasks, and yet the overlapping behaviors of primary and secondary care partners warrant the need to engage secondary care partners in FRM interventions. Current dementia care partner research and the majority of interventions target primary care partners (Gallagher-Thompson et al., 2020; Gaugler et al., 2003). However, the study suggests that secondary care partners also play an essential role in FRM for community-dwelling OLWD, which points to opportunities for the development of new FRM interventions and programs to support secondary care partners and facilitate collaborations between primary and secondary care partners.

### **The Dimensionality of FRM behaviors**

This study also examined the dimensionality of FRM behaviors (See Figure 2.2). Seven domains were identified. Five of these domains align with the behavioral framework proposed in the previous qualitative study (Zhou, 2021): functional mobility assistance, physical environment modification, health promotion support, learning, and self-adjustment.

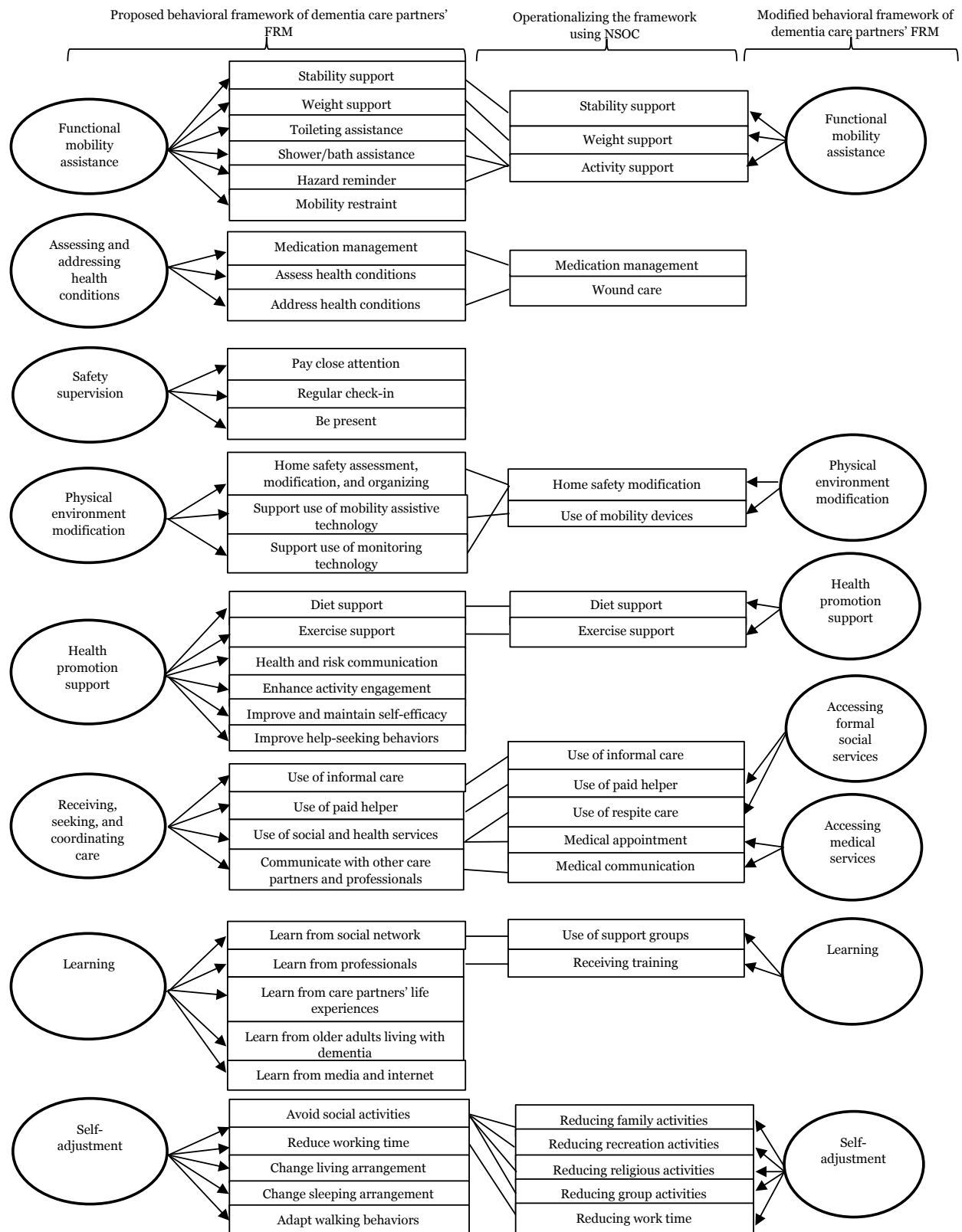
The first reason for the discrepancy was that qualitative study yielded more domains and more nuanced FRM behaviors than which were measured in NSOC 2015. Specifically, there were no survey questions in NSOC 2015 describing care partners' efforts in safety supervision. There were limited survey questions in NSOC describing how care partners assessed and addressed health conditions for OLWD, which could not support exploring the complexity of this domain of FRM behaviors. Future research should utilize comprehensive and validated measures to understand care partners' behaviors in assessing and addressing OLWD's health conditions (Sadak et al., 2016).

Another reason for the discrepancy is one domain of FRM behaviors identified in the qualitative study, "receiving, seeking, and coordinating care", was revealed in the

current study to be multi-faceted. It was thus broken down into the following three domains of FRM behaviors: accessing medical care (making medical appointments and medical communication), accessing formal social care (use of paid care, use of respite care), and use of informal care based on the EFA analysis. This study found no strong associations between care partners' adoptions of different kinds of social and health care and services, which suggests that these new categories are distinctive and should not be combined. These findings illustrate the need to explore different mechanisms, facilitators, and barriers for care partners' help-seeking from informal networks (Friedman & Kennedy, 2021), community formal services (Røsvik et al., 2020), and healthcare services, such as occupational therapy, and physical therapy (Ganz et al., 2008) when engaging them in FRM.

Noticeably, medication management was a complex variable as it was loaded to factor "accessing medical services" and "health promotion support". Previous studies have also described the complexity of medication management as it often involves interacting with healthcare systems, collaboration with OLWD, and challenges of engaging in clinical decision-making (Gillespie et al., 2014; Lee et al., 2019). The associations among medication management, accessing medical services, and health promotion point to the need to provide comprehensive support for care partners to assist pharmacological treatment, develop partnerships with healthcare providers (Griffin et al., 2019; Sadak et al., 2015), as well as adopt non-pharmacological interventions, such as exercise, and nutrition management in FRM (Fares, 2018), rather than focusing on only one domain.





**Figure 2.2.** Modified behavioral framework of dementia care partners' fall risk management

## **How the Dimensionality of FRM Behaviors Differs between Primary and Secondary Care Partners**

The EFA using sub-samples of primary and secondary care partners also illustrated the different behavioral patterns for FRM between primary and secondary care partners. Primary care partners' behavioral patterns have more dimensions than those of secondary care partners. This may be because primary care partners often provide comprehensive care to OLWD as they often play a role as "gatekeepers" and they get involved in most care activities when needed (Stommel et al., 1995). Another possible explanation is they are often expected to take on a comprehensive set of responsibilities by other care partners (Tatangelo et al., 2018). Secondary care partners might have more specialization in providing support in certain aspects of care and have a greater variation in the level of support provided (Stommel et al., 1995). For example, some secondary care partners might provide extensive support to OLWD and their primary care partners, involving multiple domains of FRM simultaneously; some others might provide limited help, focusing on one or two domain, such as functional mobility assistance, or taking care of some medical-related care tasks (Friedman & Kennedy, 2021).

These findings indicate the facilitators and barriers for primary and secondary care partners to adopt FRM behaviors might also differ and require further exploration. This knowledge will allow future interventions to be adapted based on their caring roles and the allocation of caring responsibilities among multiple care partners.

## **Limitations**

The study has limitations. First, I was not able to examine all the FRM behaviors proposed in the behavioral framework in the previous study (Zhou, 2021), see Figure

2.2. Additionally, these survey questions were also not designed specifically to target care partners' engagement in FRM, for example, care partners' assistance in making medical appointments, medical communications, and use of support groups might not be all relevant to FRM. These behaviors were identified as FRM behaviors based on a previous qualitative study (Zhou, 2021), care partners might unintentionally adopt these behaviors and these efforts might benefit OLWD in FRM. Future research needs to examine the impact of these behaviors on fall risk reduction and compare the impact of these behaviors when adopted intentionally and unintentionally. Another limitation of the study is the binary variables of FRM behaviors and the fact that all were based on care partners' self-report. These measures were not able to reflect care partners' heterogeneous experiences in FRM and various levels of engagement in FRM behaviors.

The NHATS 2015 and the NSOC 2015 provide the best available data to validate the behavioral framework for dementia care partners' FRM. These limitations mentioned above warrant the need to develop a comprehensive study that is specific to dementia care partners' engagement in FRM behaviors and using more accurate and objective measures, such as asking care partners to report the frequencies of adopting FRM behaviors or using ecological momentary assessment, which assesses individuals' current experiences and behaviors as they occur in real-time and in their natural environment (Burke et al., 2017).

### **Conclusion and Implications**

The study findings contribute to improving the understanding of care partners' FRM for community-dwelling OLWD. The study provides important information about fall risk among community-dwelling OLWD who have care partners and the prevalence

of care partners' FRM behaviors using a nationally representative sample. Varied prevalence of different FRM behaviors identified areas that interventions can be developed built upon their existing efforts, as well as under-utilized FRM behaviors for which care partners might need additional support and guidance.

The study also examined the dimensionality of care partners' FRM behaviors, which provides essential guidance for future research, measurement, and intervention development. The study validates five domains of FRM proposed in prior study, identifies the associations among medication management, health promotion, and accessing medical services, and the complexity of "receiving, seeking, and coordinating care". This framework can also be used to examine the impact of care partners' engagement in FRM, either each FRM behavior or each domain of FRM behaviors, on fall-related outcomes among community-dwelling OLWD. For those that are tested effective in FRM, the following steps will be developing interventions to engage these FRM behaviors to a greater degree. For those for which evidence is as yet lacking for their efficacy, further exploration about the associations between these FRM behaviors and fall-related outcomes are needed in order to provide guidance to care partners if they utilize these behaviors for managing fall risk.

Furthermore, this study identified important similarities and differences between primary and secondary care partners' sociodemographic characteristics, the prevalence of FRM behaviors, and their behavioral patterns of FRM. These findings highlight the need to further understand how sociodemographic characteristics impact primary and secondary care partners' participation in FRM differently. This information will inform interventions that can effectively engage care partners with different caregiving roles in diverse contexts. The comparison between the health conditions of

primary and secondary care partners confirms the need to further understand how caring for OLWD impacts secondary care partners and what can be done to mitigate negative impacts. The study highlights the critical role of primary care partners in adopting comprehensive strategies in FRM, especially in diet support and medical care-related tasks. The findings also point out the critical role of secondary care partners in FRM. These findings emphasize the need to include both primary and secondary care partners and facilitate better communications and collaborations between them in FRM interventions and programs. Besides possibly easing the burden of primary care partners, maintaining health and well-being for community-dwelling OLWD, reducing OLWD's risk of falling, and delaying their nursing home placement, it is essential to address the overlooked need of secondary care partners (Gaugler et al., 2003), their hope to provide more care for OLWD (Bédard et al., 2001; Gonçalves-Pereira et al., 2020; Marino et al., 2020), and recognize their contributions (Stommel et al., 1995).

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## **PAPER THREE.**

### **CARE PARTNERS' FALL RISK MANAGEMENT AND FALL-RELATED OUTCOMES AMONG COMMUNITY-DWELLING OLDER ADULTS LIVING WITH DEMENTIA**

#### **Introduction**

Falls among adults ages 65 years and older are a major cause of morbidity and injury-related mortality (Pande et al., 2006). Older adults living with dementia (OLWD) are at particularly high risk of falling (Allan et al., 2009). However, falls and dementia are considered to be discrete conditions with their evaluation and management provided separately despite falls being a common problem for people living with dementia (Casey et al., 2020). About 47% of people living in the community with Alzheimer's disease fall at least once every year (Passini et al., 1995). Older adults living with Alzheimer's disease sustain nearly three times the number of fall-related fractures than those who do not have cognitive impairment (Ryan et al., 2011). In addition, OLWD have a poorer prognosis once a fall has occurred. Compared with community-dwelling OLWD who do not fall, those who fall have a higher risk of functional decline and are approximately five times more likely to be placed in residential care settings (Morris et al., 1987). Furthermore, the risk of falling among OLWD heightens the care burden for their informal care partners (Kamiya et al., 2014; Leggett et al., 2018; Zhou et al., 2020). However, there is limited evidence of effective interventions to reduce the risk of falling among this population.

There are multiple factors that impact OLWD's risk of falling. A 2020 review (Casey et al., 2020) summarized these factors into three categories: (1) *those shared between older adults with and without dementia*: age and age-related changes, sensory impairment, chronic illnesses and frailty, unsupportive footwear, alcohol consumption,

history of falls, fear of falling, (2) *those more pronounced in persons with dementia*: gait and balance impairment, autonomic dysfunction/orthostasis, visuospatial deficits, central nervous system (CNS)-active medications, home and environment safety, improper assistive device use, functional deficits, diabetes, depression, female sex, and (3) *those unique in persons with dementia*: type of dementia, neuropsychiatric symptoms of dementia, sedentary behaviors, unmet needs, and caregiver burden. Apart from these well-characterized factors, there is an understudied factor that might be associated with community-dwelling OLWD: the engagement of OLWD's informal care partners, including partner/spouse, family, friends, neighbors, and other unpaid care partners (hereafter referred to as "care partner") (Zhou et al., 2020).

Dementia often impacts individuals' ability to safely and independently carry out daily activities, necessitating the involvement of people to provide assistance. In the United States, most OLWD reside at home and are cared for by care partners (Hebert et al., 2013). They not only provide support with older adults' daily activities but also address medical and psychiatric comorbidities that commonly occur in OLWD that require complex management and coordination (Sadak et al., 2016). One study showed that high levels of informal care receipt were associated with a 54% fall-related injuries risk reduction among community-dwelling older adults living with cognitive impairment (Hoffman et al., 2017). However, the study operationalized receipt of informal care by caregiving time and not by caregiving activity. It is unclear what care partners do that can reduce the risk of falling for OLWD. To ensure care meets the needs of those with dementia living in the community, the content in addition to the quantity of care received needs to be examined (Reckrey, Bollens-Lund, et al., 2020).

Some studies have suggested that care partners adopted multi-level, multi-domain behaviors in managing fall risk for community-dwelling OLWD (Meyer et al., 2015; Zhou et al., 2020). These care partners' behaviors are potentially modifiable factors that future fall prevention interventions could target (Zhou, 2021a, 2021b). However, previous studies have not examined the possible impact of these fall risk management (FRM) behaviors on fall-related outcomes among community-dwelling OLWD. Understanding how care partners' FRM behaviors are associated with fall risk reduction for OLWD would allow researchers, practitioners, and policymakers to develop more efficacious fall prevention programs. The study aims to assess fall risk reduction for OLWD associated with receipt of FRM support from their care partners.

## **Conceptual Framework**

### **Theory of Health Behavior in an Ecological Context**

The theory of health behavior in an ecological context (Simons-Morton, 2013) was used to inform the exploration of the impact of care partners' FRM behaviors on fall risk-related outcomes. This framework suggests that health-related behaviors, adopted intentionally or unintentionally, could affect the health of others.

### **The Behavioral Framework for Dementia Care Partners' Fall Risk Management**

Two prior studies (Zhou, 2021a, 2021b) proposed and validated a behavioral framework for dementia care partners' FRM, identifying ten domains of care partners' FRM behaviors. These behaviors include:

- Functional mobility assistance, defined as care partners physically or verbally assisting OLWD to perform movements in the environment; this could

include standing, walking, toileting, shower/bath assistance, hazard reminder, or mobility restraint.

- Assessing and addressing health conditions, defined as care partners assessing and addressing OLWD's mental and physical health conditions before and after OLWD's fall incidents.
- Health promotion support, defined as care partners enabling OLWD to increase control over and to improve their own health; this includes health and risk communication, enhancing activity engagement, exercise support, diet support, improving and maintaining OLWD self-efficacy, and improving their help-seeking behaviors.
- Safety supervision, defined as care partners being able, ready, and willing to perform intentional acts to reduce injury risk to OLWD; it includes paying close attention, regular check-in, and being present.
- Physical environment modification, defined as care partners modifying physical aspects of the environment that OLWD interact with; it includes home safety assessment, modification, and organizing, ensuring the safety of the shoes, and support OLWD's use of mobility and monitoring technology.
- Use of informal care, defined as care partners receive and ask for help from other families or friends to support OLWD.
- Use of formal social care, defined as care partners utilizing paid social care to provide support for OLWD when they are not available or need to take a break, such as paid helper and respite care.



- Use of medical care, defined as care partners receiving or seeking help from healthcare providers.
- Learning, defined as care partners gaining information and skills from past experience and the outside world, such as learning from professional care providers, care partners' own life experiences, OLWD, social network, as well as resources online or in the media.
- Self-adjustment, defined as changing their arrangements of living, sleeping, working, and social and physical activities in response to the fall risk of OLWD.

This framework also accounts for the fact that dementia care partners adopt fall risk prevention behaviors at different stages, including support before dementia diagnosis, preventing falls, preparing to respond to falls, and responding to falls. When OLWD start to experience a high risk of falling, care partners might focus on preparing to respond to OLWD's fall incidents as they think their loved one "is going to fall no matter what (Zhou, 2021a)". Such understanding came from some care partners' lived experiences, but not yet validated. It is also unknown if and when fall prevention efforts may stop being beneficial (Casey et al., 2020).

A study by this author validated this framework by examining the associations between multiple FRM behaviors in each domain and found that behaviors within each domain were often adopted simultaneously (Zhou, 2021b). A single behavior might be too small to detect, but the cumulative effects of multiple behaviors within each domain might be large enough to detect. Therefore, this paper will examine both (1) the associations between individual FRM behaviors and OLWD's fall-related outcomes, and

(2) the associations between each domain of FRM behaviors and OLWD's fall-related outcomes.

### **Definition of Falls and the Fall-related Outcome Framework**

Lay people and medical professionals may have different definitions of falls (Ballinger & Payne, 2002). According to the consensus reached by Falls Network Europe, a fall is defined as “an unexpected event in which the participants come to rest on the ground, floor, or a lower level” (Lamb et al., 2005). It can be assessed by the number of falls, the number of fallers/ non-fallers/ frequent fallers, fall rate per person-year, or time to first fall. As falls may have other consequences, fall prevention trials should also contain other relevant outcomes. The Falls Network Europe proposed an outcome framework for fall injury prevention, which includes number/rate of falls, fall injury, physical activity, psychological consequences (such as self-efficacy, fear of falls, activity limitations), and generic health-related quality of life (such as Short Form 12 – SF12, or European Quality of Life Instrument - EQ-5D) (Lamb et al., 2005).

According to the report, physical activity represents autonomy and independence (Lamb et al., 2005). Psychological consequences are important to consider when managing fall risk as many older adults experience psychological difficulties related to falls (Jørstad et al., 2005). These quality of life measures include assessment of physical health and mental health (SF-12) (Haywood et al., 2005), mobility, self-care, pain, usual activities, and psychological status (EQ-5D) (EuroQol Group, 1990). Health-related quality of life is an important outcome as it is likely to capture unanticipated effects of fall injury prevention interventions (Lamb et al., 2005). Another note suggested by this outcome framework is the time points for follow-up. Fall-prevention interventions require long-term follow-up (12 months) as they might have a delayed effect.

While care partners often take action to mitigate fall risk, these interventions are neither formally designed nor professionally delivered. However, their efforts might also bring therapeutic or preventive benefits to OLWD (Gitlin & Hodgson, 2015). This outcome framework and suggested 12-month follow-up time point can be used to examine how care partners' FRM support is associated with different fall-related outcomes.

### **Study Hypotheses**

Utilizing the theory of health behavior in an ecological context, the behavioral framework for dementia care partners' FRM, and the fall-related outcome framework, I test the following 3 hypotheses:

- (1) For every one more care partner providing each single behavior of FRM support, there will be reduced likelihood of falls, lower level of negative psychological consequences of falls, higher level of physical activities, and high level of health-related quality of life.
- (2) For every one more care partner providing any behaviors within each domain of FRM support, there will be reduced likelihood of falls, lower level of negative psychological consequences of falls, higher level of physical activities, and high level of health-related quality of life.
- (3) Care partners' FRM have stronger associations with fall risk reduction for community-dwelling OLWD who had no falls, or 1 fall compared to those who had multiple falls in the last 12 months.

## **Methods**

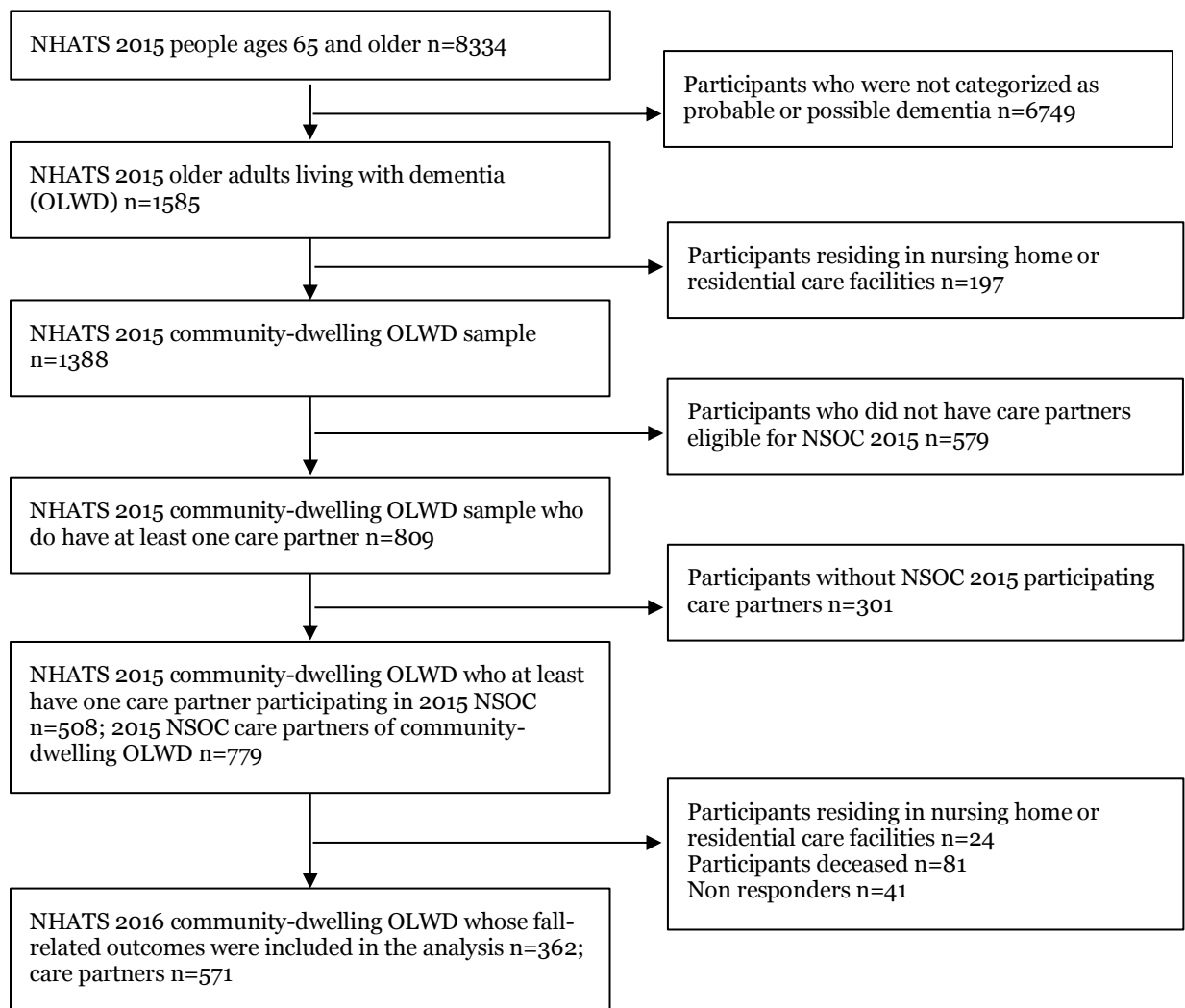
### **Study Population and Data Collection**

Data on community-dwelling OLWD are from NHATS 2015 and 2016 round public use files. The NHATS is sponsored by the National Institute on Aging through a cooperative agreement with the Johns Hopkins Bloomberg School of Public Health. The NHATS was designed to follow successive nationally representative cohorts of people ages 65 and older and enrolled in Medicare, with an oversampling of non-Hispanic Black older adults and those aged 85 and older. The NHATS have been administered annually since 2011, using in-person interviews designed to collect detailed information on the disablement process and its consequences (Montaquila et al., 2012). Response rates are 73.2% in 2015 and 88.2% in 2016.

Data on OLWD's care partners are from the 2015 National Study of Caregiving (NSOC) sensitive data files. Respondents from NHATS might identify up to five individuals who provided the respondent with assistance in personal care or household tasks (Kasper & Freedman, 2014; Wolff et al., 2016). Those caregivers were then administered a 30-minute telephone survey that included questions on caregiving activities, duration and intensity, support services sought and used, effects on caregiver's participation in activities including work, and personal and household demographics. There have been three waves of NSOC surveys in 2011, 2015, and 2017. Response rates for NSOC 2015 are 63%.

I used three criteria to identify community-dwelling OLWD from NHATS (1) a classification of probable or possible dementia based on the dementia classification criteria in the NHATS (Kasper et al., 2013), (2) community-dwelling, not residential

care or nursing home, and (3) if they have at least one care partner, included in NSOC 2015 (See Figure 3.1).



*Figure 3.1.* Diagram showing flow of participants included in the study.

Data used to classify cognitive status included self- or proxy-report of medical provider-diagnosed dementia or Alzheimer’s disease, the Eight-Item Interview to Differentiate Aging and Dementia screening questionnaire (Galvin et al., 2005), and clinical tests of memory, orientation, and executive functions (Kasper et al., 2013). These criteria are validated for use in community-based epidemiological surveys (Kasper et al., 2013). Linking NSOC 2015 data with OLWD data, 508 community-

dwelling OLWD and their 779 care partners were identified. In 2016, for these 508 OLWD, 362 remained living in the community and participated in NHATS 2016 survey. For these 362 OLWD, their outcomes were assessed and included in the analysis. Twenty-four participants moved into residential care or nursing homes, 81 participants died, and 41 participants were missing from the sample.

Among the 362 OLWD included in the analysis, 116 of the remaining sample had proxies help with responding to survey questions in circumstances where the participants could not respond, typically due to health or memory problems. A proxy was someone familiar with the participants' health, daily routine, care arrangement, and preferably lived with the participants. The current secondary data analysis using these data was deemed not human subjects research by the University of Washington institutional review board as all data are de-identified.

## **Measures**

### **Primary Outcome.**

NHATS participants (or proxies) reported if they fell in the last 12 months/since the last interview month and year. This question was prefaced by the following definition: "By falling down, we mean any fall, slip, or trip in which you lose your balance and land on the floor or ground at a lower level (1=yes, 0=no)." An additional question was asked: "In the last 12 months/since the last interview month and year, has the participant fallen down more than one time (1=yes, 0=no)?" These variables were from the survey NHATS 2016 to examine the delayed effect of care partners' FRM support (Lamb et al., 2005).

### **Secondary Outcomes.**

Based on the conceptual framework of the study, secondary outcome variables were selected from NHATS 2016. One outcome suggested in the framework, fall injuries, was not included in the analysis as this information was not available in NHATS 2016 public or sensitive data.

***Psychological consequences of falls.***

Two indicators were used: fear of falling and activity limitations due to fear of falling. NHATS participants (or proxies) were asked if they worried about falling down in the last month (yes/no), and if this worry ever limited their activities (yes/no).

***Physical activities.***

“In the last month, did you ever go walking for exercise?” and participants provided “Yes” or “No” or “Don’t know” responses. No walking exercises was coded as 1 and having walking exercise in the last month was coded as 0.

***Health-related quality of life.***

While NHATS did not include standardized measures of health-related Quality of Life (QoL) (e.g., SF12), I selected four indicators that constitute overall QoL, including self-rated health, pain, anxiety, and depression (Schwartz et al., 2019). For self-rated health, participants were asked to self-report their health as “poor”, “fair”, “good”, “very good”, “excellent”. “Fair” and “poor” were coded as “1” and the rest were coded as “0”. For pain, participants were asked if they were bothered by pain in the last month. Anxiety was measured using the GAD-2 score (range 0-6); score  $\geq 3$  indicated they experienced anxiety symptoms within the last months. Depression was measured using the PHQ-2 scale (range: 0-6); score  $\geq 3$  indicated they had depressive symptoms within the last month (Kroenke et al., 2009).

***Independent variables.***

Based on the behavioral framework proposed in a previous study (Zhou, 2021a, 2021b), twenty-one FRM behaviors in ten domains were identified by matching the

definitions of these behaviors and existing survey questions in NSOC 2015 (Appendix 3.1). These FRM behaviors include: (1) functional mobility assistance, including stability support, weight support, and mobility support; (2) health promotion support, including diet support, exercise support; (3) medication management; (4) wound care; (5) use of medical care: medical appointment, and medical communication; (6) use of formal social care including paid or respite care; (7) use of informal care; (8) learning in the form of using support groups or receiving training; (9) physical environment modification, including home safety modification and use of mobility device; and (10) self-adjustment, including reducing family activities, recreation activities, religious activities, group activities, and work time. Medication management and wound care were originally categorized as care partners' efforts to "assess and address health conditions" when managing fall risk for OLWD based on the initial framework (Zhou, 2021a, 2021b). However, they were not grouped into the same category in this exploratory factor analysis based on the validation of this framework (Zhou, 2021b). Therefore, in the analysis of this study, they are viewed as two domains of FRM behaviors. Use of informal care was not loaded with any other behaviors (Zhou, 2021b); therefore, it is viewed as one distinctive domain of FRM behaviors.

Most of these variables were binary as they asked care partners if they adopted certain behaviors. "Refused" or "Don't Know" responses were coded as "No", assuming care partners who refused to answer these questions or reported "don't know" are less likely to adopt these FRM behaviors. Only one variable (activity assistance) was originally an ordinal variable (how often did you help the older adult get around? 1 every day, 2 most days, 3 some days, 4 rarely, 5 never). For consistency in analysis, the variable was recoded into a binary variable (1-3 coded as 1, 4-5 coded as 0).



Some OLWD might have more than one care partner adopting the same FRM behaviors. For each OLWD, all their care partners' behaviors were aggregated into a count variable from 0-5, representing the level of support OLWD received in one single FRM behavior. For example, if one OLWD had two care partners providing stability support, this OLWD would be assigned a score of two representing this OLWD received stability support from two care partners.

To examine the cumulative effect of care partners' FRM behaviors within each domain, scores for individual FRM behaviors were aggregated into a score representing the level of support in a domain of FRM for each OLWD. For example, if one OLWD had two care partners providing stability support, one care partner providing weight support, and three care partners providing mobility support, this OLWD would be assigned a score of six to represent the level of functional mobility assistance they received.

### **Covariates and the moderating variable.**

Covariates were chosen based on their relevance to fall risk among OLWD, and their availability in NHAT 2015 and NSOC 2015. An initial set of variables were selected based on previous literature, including: (1) sociodemographic factors: age, gender, race/ethnicity, education (Hoffman et al., 2017; Horton, 2007; Sun et al., 2016); (2) physical health: physical function measured by short physical performance battery (SPPB score), slow gait speed (1m/s or below) (Taylor et al., 2018), comorbidity, diabetes, arthritis, stroke, heart problem, high blood pressure, fall history last year, use of mobility device, self-rated balance, pain, visual impairment, hearing impairment (Casey et al., 2020); (3) psychological factors: fear of falling, depression, anxiety, cognitive function, behavioral disturbance (Casey et al., 2020; Eriksson et al., 2007;

Whitney et al., 2012); (4) social factors: caregiving time received, depression of primary care partners, adverse consequences of unmet need in activities of daily living (ADL), activity of daily living (IADL), mobility, and any of these domains (ADL, IADL, mobility), live alone, informal social engagement, formal social engagement (Casey et al., 2020; Horton, 2007; Maggio D et al., 2010; Sun et al., 2016); (5) physical environment: home tripping hazards, outdoor tripping hazards (Chippendale & Boltz, 2015; S. Lee et al., 2019; Wing et al., 2017).

Bivariate logistic regression was performed to examine the associations between these variables with primary outcomes (See Appendix 3.2). Factors that were associated with primary outcomes with p-value <0.1 were selected. These variables were assessed for multicollinearity using the Pearson correlation test. Those pairs of variables had a moderate coefficient >0.3: heart problems and the number of chronic conditions (0.400), hypertension and the number of chronic conditions (0.468), self-rated balance and adverse consequences of unmet need in ADL, IADL, and mobility (0.331), and adverse consequences of unmet need in IADL and adverse consequences of unmet need in ADL, IADL, or mobility (0.350). Only one of these two collinear variables were chosen to be included in the adjusted models to examine the impact of care partners' FRM on fall-related outcomes. Variables included from these three pairs were the number of chronic conditions and adverse consequences of unmet need in ADL, IADL, and mobility.

The final list of covariates included was gender, race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, others including American Indian/Asian/Native Hawaiian/Multi-racial), education (less than 12 years, 12 years, more than 12 years), number of chronic conditions (0-2, 3+), pain last month (yes/no), fear of falling

(yes/no), history of falls (0, 1, 2+ falls in the last year), cognitive function (low, intermediate, high), adverse consequences of unmet needs in ADL, IADL, and mobility (yes/no), and living status (alone/with others).

The measure of comorbidity was based on the number of reported medically diagnosed chronic health conditions, including heart attack, heart diseases, hypertension, arthritis, osteoporosis, diabetes, lung disease, stroke, cancer, and hip fracture (0-2 or 3 or more).

Cognitive function score was assessed by clinical tests of memory, orientation, and executive functions, categorized into low, intermediate, high, ranging from 0-32. The score was categorized into low (0-6), intermediate (7-10), and high (11-23) levels based on the tertiles of cognitive function scores.

Adverse consequences of unmet need in ADL, IADL and mobility was defined as participants having an adverse consequence of the unmet need for ADL (eating, showering/taking a bath/washing up, getting to or using the toilet, and dressing), IADL (laundry, shopping for groceries or personal items, meal preparation, keeping track of medication), and mobility assistance (going outside the home, getting around inside the home, and getting out of bed). Care partners reported they needed assistance with an ADL, IADL and mobility activity and reported a corresponding adverse consequence when help was unavailable. Adverse consequences include went without eating, went without showering/taking a bath/washing up, wet or soiled clothes, went without getting dressed, went without groceries or personal items, went without a hot meal, made a mistake in taking prescribed medication, had to remain inside, did not move around inside the home, and had to stay in bed.

History of falls was an ordinal variable generated by two survey questions from NHATS 2015. OLWD were asked if they fell in the last 12 months/since the last interview month and year, and if they fell multiple times (0 represents no fall last year, 1 represents one fall last year, and 2 represents two or more falls last year). As the study aimed to examine how the history of falls impact the associations between care partners FRM behaviors and fall risk reduction, history of falls was a covariate as well as a moderating variable that was used to conduct subgroup analysis, categorizing the analytic sample into three groups that had no fall, one fall, and two or more falls last year in 2015.

### **Statistical Analysis**

The participants' baseline characteristics were summarized using weighted means and standard deviations or unweighted frequencies and weighted percentages. Baseline characteristics were also separated into three groups based on the number of falls in 2015 (no falls, 1 fall, 2 or more falls). The scores representing the level of support in a single FRM behavior received by the OLWD were summarized as unweighted frequencies and weighted percentages and also separated into three groups (participants reported no falls, 1 fall, or 2 or more falls in NHATS 2015). Comparisons between groups were performed using independent sample t-tests and Chi-square tests for trend.

Adjusted logistic regression was performed to examine the associations between receipt of care partners' FRM support and fall-related outcomes for community-dwelling OLWD using the full sample (n=362). The level of support in each single FRM behavior and each domain of FRM behaviors were examined separately after adjusting for covariates. Subgroup analyses based on 12-month fall history were conducted to

examine the associations between FRM support and OLWD's fall outcomes (primary outcomes) after adjusting for all covariates.

The data were weighted to account for the complex survey design, adjust for oversampling, survey nonresponse, and post-stratification. For all analyses, statistical significance was determined by  $\alpha < .05$  in a 2-sided hypothesis. Among 362 OLWD's outcomes included in the analysis, 0.2-2% of data were missing overall across all of the characteristic variables and 8.5% for the variable cognitive functions. No imputation was performed on missing items. All statistical analyses were performed using STATA 15.0 (StataCorp, 2018).

As the study involved analysis with multiple outcomes, multiple independent variables, and sub-group analysis, the study includes 420 hypotheses in total, which suggests close to 100% of probability that at least one of the significant findings were actually not significant. Bonferroni corrections on post hoc tests were used to assess the risk of type 1 error from repeated hypotheses by dividing the p-value by the number of tests:  $0.05/420=0.0001$  (Streiner, 2015).

I explored nonresponse in NHATS 2016 for the 508 community-dwelling OLWD identified from NHATS 2015. There are three reasons for missing data: institutionalization (n=24), mortality (n=81), and non-response (n=41). Using multinomial logistic regression (Kwak & Clayton-Matthews, 2002), I found that age, gender, race/ethnicity, education, and living alone are associated with nonresponse in NHATS 2016, but there were no significant associations between history of falls and nonresponse for any reason (See Appendix 3.3).

## **Results**

### **Participants**

Full descriptive statistics of sample baseline characteristics by the history of falls can be found in Table 3.1. In NHAIST 2015, 266 (52%) of 508 OLWD had no fall in the last year, 103 (20%) had one fall, and 138 (27%) had more than two falls. OLWD average age was 81.3 (range 65-107) and 56.6% were female. Approximately 66.0% were non-Hispanic White, 19.6% non-Hispanic Black, 8.6% Hispanic, and 5.9% participants were American Indian, Asian, Native Hawaiian, and Multi-racial groups. Approximately 37.8% of OLWD had less than a high school education, 33.2% had a high school degree, and 29.0% had more than 12 years of education. Sixty-six percent had three or more chronic conditions and 67% of participants reported having pain in the last month. Forty-four percent experienced fear of falling and 37.8% of participants had adverse consequences due to unmet need in ADL, IADL, or mobility in the last month. About 14.4% participants lived alone.

Fall history varied by participants' gender, race/ethnicity, number of chronic conditions, fear of falling, and adverse consequences due to unmet needs in ADL, IADL, or mobility (Table 3.1). Those who had no fall in the last year were more likely to be female (no falls 63.2% vs. one fall 61.3% vs. 2+ falls 42.8%,  $p=0.005$ ). Those who had 2 or more falls in the last year were more likely to be non-Hispanic White (2+ falls 75.2% vs. 1 fall 77.0% vs. no falls 55.2%,  $p=0.008$ ). Those who had 2 or more falls were more likely to report fear of falling (2+ falls 62.0% vs. 1 fall 39.9% vs. no falls 34.7%,  $p=0.000$ ).

Table 3.1. Comparison of participants' baseline characteristics by 12-month fall history (n=508 from NHATS 2015)

|                                                                       | Mean (SD) or<br>n (%)                                 | 12-month fall history (n=507) |                   |                            | P-value <sup>c</sup> |
|-----------------------------------------------------------------------|-------------------------------------------------------|-------------------------------|-------------------|----------------------------|----------------------|
|                                                                       | Total<br>(n=508)                                      | No falls<br>(n=266)           | 1 Fall<br>(n=103) | 2 or more falls<br>(n=138) |                      |
| <b>Age (n=508)<sup>a</sup></b>                                        | Mean: 81.3<br>(SD: 7.1)<br>Range: 65-107 <sup>b</sup> | 82.1 (7.1)                    | 82.0 (6.6)        | 79.5 (6.8)                 | 0.083                |
| <b>Female (n=508)</b>                                                 | 323 (56.6%) <sup>d</sup>                              | 182 (63.2%)                   | 68 (61.3%)        | 72 (42.8%)                 | 0.005 <sup>**e</sup> |
| <b>Race/ethnicity (n=506)</b>                                         |                                                       |                               |                   |                            | 0.008 <sup>**</sup>  |
| Non-Hispanic White                                                    | 252 (66.0%)                                           | 105 (55.2%)                   | 63 (77.0%)        | 83 (75.2%)                 |                      |
| Non-Hispanic Black                                                    | 199 (19.6%)                                           | 127 (26.2%)                   | 30 (13.0%)        | 42 (14.0%)                 |                      |
| Hispanic                                                              | 37 (8.6%)                                             | 22 (11.5%)                    | 6 (5.9%)          | 9 (5.9%)                   |                      |
| Other (American<br>Indian/Asian/Native<br>Hawaiian/Multi-racial)      | 18 (5.9%)                                             | 10 (7.2%)                     | 4 (4.2%)          | 4 (5.1%)                   |                      |
| <b>Education (n=501)</b>                                              |                                                       |                               |                   |                            | 0.375                |
| <12 years                                                             | 226 (37.8%)                                           | 124 (39.6%)                   | 48 (41.6%)        | 54 (32.7%)                 |                      |
| 12 years                                                              | 143 (33.2%)                                           | 79 (36.1%)                    | 30 (29.6%)        | 34 (31.4%)                 |                      |
| >12 years                                                             | 132 (29.0%)                                           | 58 (24.3%)                    | 24 (28.8%)        | 49 (36.0%)                 |                      |
| <b>Number of chronic<br/>conditions, 0-9 (n=504)<sup>f</sup></b>      |                                                       |                               |                   |                            | 0.046 <sup>*</sup>   |
| 0-2                                                                   | 176 (34.4%)                                           | 99 (37.4%)                    | 37 (41.9%)        | 40 (24.9%)                 |                      |
| 3+                                                                    | 328 (65.6%)                                           | 164 (62.6%)                   | 65 (58.1%)        | 98 (75.1%)                 |                      |
| <b>Pain (n=506)</b>                                                   | 317 (66.9%)                                           | 155 (62.7%)                   | 61 (62.4%)        | 100 (76.2%)                | 0.051                |
| <b>Fear of falling (n=506)</b>                                        | 209 (44.3%)                                           | 87 (34.7%)                    | 40 (39.9%)        | 81 (62.0%)                 | 0.000 <sup>***</sup> |
| <b>Cognitive functions (0-32)<br/>(n=457)</b>                         |                                                       |                               |                   |                            | 0.142                |
| Low (0-6)                                                             | 164 (32.9%)                                           | 97 (39.6%)                    | 28 (28.9%)        | 39 (25.1%)                 |                      |
| Intermediate (7-10)                                                   | 144 (30.3%)                                           | 63 (25.3%)                    | 36 (31.3%)        | 45 (38.1%)                 |                      |
| High (11-23)                                                          | 149 (36.8%)                                           | 81 (35.2%)                    | 29 (39.8%)        | 38 (36.8%)                 |                      |
| <b>Adverse consequences due<br/>to unmet need (n=508)<sup>g</sup></b> | 174 (37.8%)                                           | 76 (31.4%)                    | 25 (30.3%)        | 72 (52.5%)                 | 0.004 <sup>**</sup>  |
| <b>Live alone (n=508)</b>                                             | 92 (14.4%)                                            | 53 (16.2%)                    | 17 (14.4%)        | 22 (11.7%)                 | 0.515                |

*Note:*

- a. n represents the number of community-dwelling older adults living with dementia; total numbers may vary due to missing data.
- b. Mean and standard deviation were weighted; range was unweighted.
- c. T-test or Chi-square test were weighted.
- d. The frequencies were unweighted, and the percentages were weighted.
- e. \*p<0.05, \*\*p<0.01, \*\*\*p<0.001
- f. Includes doctor-identified heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, cancer, and hip fracture.
- g. Unmet needs represent unmet needs in activities of daily living, instrumental activities of daily living, and mobility.

## Receipt of Care Partners' Fall Risk Management Support

Using NSOC 2015, descriptive statistics of FRM support received by community-dwelling OLWD by 12-month fall history are presented in Table 3.2. OLWD who had multiple falls were receiving more support in the form of functional mobility assistance, including stability support (p=0.013), weight support (p=0.012), and mobility support (p=0.010). They were also more likely to receive wound care (p=0.018) from their care partners, and they had more care partners help with mobility devices (p=0.005). There were no significant differences in receipt of other care partners' FRM support.

Table 3.2. Fall risk management support received by 12-month fall history (n=508 from NHATS 2015)

|                                                 | n (%) OLWD receiving each type of fall risk management support from number of care partners (0-5) |                |               |              |             |             | Average fall risk management support received by OLWD by 12-month fall history (n=507) |        |          |              |
|-------------------------------------------------|---------------------------------------------------------------------------------------------------|----------------|---------------|--------------|-------------|-------------|----------------------------------------------------------------------------------------|--------|----------|--------------|
|                                                 | 0                                                                                                 | 1              | 2             | 3            | 4           | 5           | 0 falls<br>a                                                                           | 1 fall | 2+ falls | P-value<br>b |
| <b>Domain 1: Functional mobility assistance</b> |                                                                                                   |                |               |              |             |             |                                                                                        |        |          |              |
| 1.1 Stability support                           | 180<br>(38.7%)                                                                                    | 225<br>(42.8%) | 84<br>(15.4%) | 17<br>(2.9%) | 1<br>(0.1%) | 1<br>(0.0%) | 0.7                                                                                    | 0.8    | 1.0      | 0.013<br>* c |
| 1.2 Weight support                              | 180<br>(38.2%)                                                                                    | 226<br>(42.5%) | 81<br>(15.5%) | 18<br>(3.6%) | 2<br>(0.2%) | 1<br>(0.0%) | 0.7                                                                                    | 0.8    | 1.0      | 0.012<br>*   |
| 1.3 Mobility support                            | 174<br>(37.2%)                                                                                    | 233<br>(44.9%) | 76<br>(12.9%) | 20<br>(4.4%) | 4<br>(0.6%) | 1<br>(0.0%) | 0.8                                                                                    | 0.8    | 1.1      | 0.010<br>*   |



Table 3.2. continued

|                                                        |                |                |                |              |              |             |     |     |     |            |
|--------------------------------------------------------|----------------|----------------|----------------|--------------|--------------|-------------|-----|-----|-----|------------|
| <b>Domain 2:<br/>Health promotion support</b>          |                |                |                |              |              |             |     |     |     |            |
| 2.1 Diet support                                       | 298<br>(57.9%) | 176<br>(36.5%) | 27<br>(4.2%)   | 7<br>(1.4%)  | 0<br>(0%)    | 0<br>(0%)   | 0.5 | 0.4 | 0.5 | 0.717      |
| 2.2 Exercise support                                   | 287<br>(59.0%) | 171<br>(32.1%) | 39<br>(6.3%)   | 8<br>(2.2%)  | 2<br>(0.4%)  | 1<br>(0.0%) | 0.5 | 0.5 | 0.6 | 0.430      |
| <b>Domain 3:<br/>Medication management</b>             |                |                |                |              |              |             |     |     |     |            |
|                                                        | 94<br>(19.0%)  | 312<br>(65.3%) | 83<br>(11.8%)  | 14<br>(3.5%) | 5<br>(0.4%)  | 0 (0%)      | 1.0 | 1.0 | 1.1 | 0.661      |
| <b>Domain 4:<br/>Wound care</b>                        |                |                |                |              |              |             |     |     |     |            |
|                                                        | 318<br>(61.2%) | 155<br>(32.5%) | 33<br>(6.0%)   | 1<br>(1.9%)  | 1<br>(0.2%)  | 0<br>(0.0%) | 0.4 | 0.5 | 0.6 | 0.018<br>* |
| <b>Domain 5:<br/>Accessing medical care</b>            |                |                |                |              |              |             |     |     |     |            |
| 5.1 Making medical appointments                        | 65<br>(13.3%)  | 348<br>(70.3%) | 77<br>(12.4%)  | 15<br>(3.3%) | 3<br>(0.8%)  | 0<br>(0%)   | 1.1 | 1.1 | 1.1 | 0.763      |
| 5.2 Medical communication                              | 123<br>(25.9%) | 316<br>(61.7%) | 62<br>(10.2%)  | 7<br>(2.3%)  | 0<br>(0%)    | 0<br>(0%)   | 0.8 | 0.9 | 1.0 | 0.200      |
| <b>Domain 6:<br/>Accessing formal social care</b>      |                |                |                |              |              |             |     |     |     |            |
| 6.1 Use of paid care                                   | 345<br>(71.5%) | 133<br>(23.5%) | 22<br>(3.7%)   | 8<br>(1.2%)  | 0<br>(0%)    | 0<br>(0%)   | 0.4 | 0.4 | 0.3 | 0.474      |
| 6.2 Use of respite care                                | 375<br>(75.4%) | 110<br>(20.6%) | 16<br>(2.7%)   | 7<br>(1.4%)  | 0<br>(0%)    | 0<br>(0%)   | 0.3 | 0.4 | 0.3 | 0.558      |
| <b>Domain 7: Use of informal care</b>                  |                |                |                |              |              |             |     |     |     |            |
|                                                        | 150<br>(32.7%) | 206<br>(39.4%) | 108<br>(19.4%) | 33<br>(6.4%) | 10<br>(2.0%) | 0<br>(0.0%) | 1.0 | 1.2 | 1.0 | 0.260      |
| <b>Domain 8:<br/>Learning</b>                          |                |                |                |              |              |             |     |     |     |            |
| 8.1 Use of support groups                              | 475<br>(94.7%) | 31 (5.2%)      | 2<br>(0.1%)    | 0<br>(0.0%)  | 0<br>(0%)    | 0<br>(0%)   | 0.7 | 0.2 | 0.5 | 0.131      |
| 8.2 Receiving training                                 | 443<br>(88.9%) | 59<br>(10.2%)  | 6 (0.9 %)      | 0<br>(0.0%)  | 0<br>(0%)    | 0<br>(0%)   | 0.1 | 0.1 | 0.1 | 0.478      |
| <b>Domain 9:<br/>Physical environment modification</b> |                |                |                |              |              |             |     |     |     |            |

Table 3.2. continued

|                                       |                |                |               |              |             |             |     |     |     |        |
|---------------------------------------|----------------|----------------|---------------|--------------|-------------|-------------|-----|-----|-----|--------|
| 9.1 Home safety modification          | 211<br>(45.7%) | 227<br>(41.4%) | 58<br>(11.3%) | 11<br>(1.5%) | 0<br>(0%)   | 1<br>(0.0%) | 0.6 | 0.6 | 0.8 | 0.233  |
| 9.2 Use of mobility devices           | 200<br>(41.1%) | 227<br>(43.4%) | 66<br>(12.4%) | 13<br>(3.0%) | 2<br>(0.2%) | 0<br>(0.0%) | 0.6 | 0.9 | 0.9 | 0.005* |
| <b>Domain 10:<br/>Self-adjustment</b> |                |                |               |              |             |             |     |     |     |        |
| 10.1 Reducing family activities       | 344<br>(71.7%) | 147<br>(25.1%) | 14<br>(2.6%)  | 3<br>(0.7%)  | 0<br>(0%)   | 0<br>(0%)   | 0.3 | 0.3 | 0.4 | 0.715  |
| 10.2 Reducing recreation activities   | 369<br>(72.8%) | 124<br>(24.2%) | 14<br>(2.9%)  | 1<br>(0.2%)  | 0<br>(0%)   | 0<br>(0%)   | 0.3 | 0.3 | 0.3 | 0.724  |
| 10.3 Reducing religious activities    | 398<br>(77.1%) | 105<br>(21.7%) | 4<br>(0.9%)   | 1<br>(0.3%)  | 0<br>(0%)   | 0<br>(0%)   | 0.2 | 0.2 | 0.3 | 0.427  |
| 10.4 Reducing group activities        | 415<br>(81.6%) | 88<br>(17.5%)  | 4<br>(0.6%)   | 1<br>(0.3%)  | 0<br>(0%)   | 0<br>(0%)   | 0.2 | 0.2 | 0.3 | 0.234  |
| 10.5 Reducing work time               | 423<br>(84.6%) | 82<br>(14.8%)  | 3<br>(14.8%)  | 0<br>(0.7%)  | 0<br>(0%)   | 0<br>(0%)   | 0.1 | 0.2 | 0.2 | 0.089  |

**Note:**

- The score is based on the number of care partners providing such support to each individual OLWD. The number representing the average level of support in a single fall risk management behavior received by OLWD in each subgroup.
- T-tests were weighted.
- \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

### Fall Risk Management Support and Fall-related Outcomes among Community-dwelling OLWD

Table 3.3 summarizes the results of 252 adjusted logistic regression models to examine the associations between receipt of care partners' FRM support in the year 2015 and fall-related outcomes in the year 2016. These outcomes are fall outcomes (fall last year, multiple falls last year), psychological consequences of falls (fear of falling, activity limitation due to fear of falling), exercise (walking), and health-related quality of life (self-rated physical health, pain, anxiety, depression).

Table 3.3. Associations between receipt of care partners' fall risk management support and fall-related outcomes among community-dwelling older adults living with dementia (n=362) <sup>a</sup>

| Fall risk management support (2015)             | Fall outcomes 2016                                  | OR(95%CI)        | P-value <sup>b</sup> |
|-------------------------------------------------|-----------------------------------------------------|------------------|----------------------|
| 1.1 Stability support                           | Multiple falls last year (n=319)                    | 1.51 (1.01-2.26) | 0.0435 *             |
| 10.2 Reducing recreation activities             |                                                     | 1.79 (1.02-3.16) | 0.0416 *             |
| 10.5 Reducing work time                         |                                                     | 2.21 (1.07-4.53) | 0.0311 *             |
| <b>Domain 1: Functional mobility assistance</b> | Fear of falling (n=319)                             | 1.18 (1.03-1.36) | 0.0149 *             |
| 1.1 Stability support                           |                                                     | 1.68 (1.14-2.46) | 0.0080 **            |
| <b>Domain 2: Health promotion support</b>       |                                                     | 1.43 (1.05-1.94) | 0.0217 *             |
| 2.2 Exercise support                            |                                                     | 1.71 (1.11-2.62) | 0.0143 *             |
| 6.1 Use of paid care                            |                                                     | 1.63 (1.02-2.63) | 0.0427 *             |
| 10.1 Reducing family activities                 |                                                     | 1.73 (1.00-3.00) | 0.0487 *             |
| <b>Domain 2: Health promotion support</b>       | Activity limitations due to fear of falling (n=319) | 1.43 (1.04-1.98) | 0.0296 *             |
| 2.1 Diet support                                |                                                     | 1.83 (1.01-3.31) | 0.0458 *             |
| 2.2 Exercise support                            |                                                     | 1.60 (1.02-2.51) | 0.0425 *             |
| <b>Domain 3: Medication management</b>          |                                                     | 1.96 (1.19-3.22) | 0.0083 **            |
| 10.4 Reducing group activities                  | No walking exercise (n=319)                         | 0.48 (0.24-0.99) | 0.0457 *             |
| <b>Domain 5: Accessing medical care</b>         | Fair or poor self-reported physical health (n=319)  | 0.68 (0.52-0.89) | 0.0048 **            |
| 5.1 Making medical appointments                 |                                                     | 0.54 (0.33-0.88) | 0.0126 *             |
| 5.2 Medical communication                       |                                                     | 0.56 (0.35-0.89) | 0.0145 *             |
| 8.1 Use of support groups                       | Anxiety (n=309)                                     | 0.19 (0.04-0.88) | 0.0333 *             |
| <b>Domain 10: Self-adjustment</b>               | Depression (n=309)                                  | 1.46 (1.23-1.74) | 0.0000 ***           |
| 10.1 Reducing family activities                 |                                                     | 2.12 (1.24-3.63) | 0.0063 **            |
| 10.2 Reducing recreation activities             |                                                     | 2.37 (1.31-4.28) | 0.0042 **            |
| 10.3 Reducing religious activities              |                                                     | 3.55 (1.77-7.10) | 0.0004 ***           |
| 10.4 Reducing group activities                  |                                                     | 2.87 (1.41-5.84) | 0.0037 **            |
| 10.5 Reducing work time                         |                                                     | 4.80 (2.47-9.32) | 0.0000 ***           |

**Note:**

- Adjusted for variables gender (n=362), race/ethnicity (n=360), education (n=356), pain (n=360), fear of falling (n=361), cognitive functions (n=331), number of chronic conditions (n=358), adverse consequences due to unmet needs (n=361), live alone (n=362), and history of falls (n=383).
- \*p<0.05, \*\*p<0.01, \*\*\*p<0.001; four digits after decimals of p-value were reported to allow for Bonferroni corrections. Bonferroni corrections on post hoc tests were used to assess the risk of type 1 error from repeated hypotheses by dividing the p-value by the number of tests: 0.05/420=0.0001.

Receiving stability support was significantly associated with having multiple falls (OR=1.51; 95% CI[1.01, 2.26],  $p=0.044$ ) the following year. Having a greater number of care partners reducing their recreation activities (OR=1.79; [1.02, 3.16],  $p=0.042$ ) and reducing their work time (OR=2.21; [1.07, 4.53],  $p=0.031$ ) were also significantly associated with a high risk of multiple falls for OLWD. No significant associations were found between any other type of FRM support and OLWD's fall outcomes.

The receipt of care partners' support in functional mobility assistance (OR=1.18; [1.03, 1.36],  $p=0.015$ ) and health promotion (OR=1.43; [1.05, 1.94],  $p=0.022$ ) were significantly associated with having a fear of falling. Specifically, receiving stability support (OR=1.68, [1.14, 2.46],  $p=0.008$ ) and receiving exercise support (OR=1.71; [1.11, 2.62],  $p=0.014$ ) were significantly associated with fear of falling. The receipt of health promotion support (OR=1.43; [1.04, 1.98],  $p=0.030$ ) and medication management (OR=1.96; [1.19, 3.22],  $p=0.008$ ) were significantly associated with OLWD's activity limitation due to fear of falling. Additionally, use of paid care (OR=1.63, [1.02, 2.63],  $p=0.043$ ) and reducing family activities (OR=1.73, [1.00, 3.00],  $p=0.049$ ) were significantly associated with OLWD's fear of falling.

Care partners' reducing group activities were significantly associated with more walking exercises for OLWD (OR=0.48, [0.24, 0.99],  $p=0.046$ ). Care partners' support in accessing the medical care (OR=0.68; [0.52, 0.89],  $p=0.005$ ) was significantly associated with better OLWD's self-rated physical health. Care partners' use of support groups was significantly associated with lower reports of anxiety among OLWD (OR=0.19; [0.04, 0.88],  $p=0.033$ ).

None of these associations above remained significant after correction for multiple comparisons via the Bonferroni method. Care partners' self-adjustment was

associated with higher reports of depression among OLWD (OR=1.46; [1.23, 1.74],  $p=0.000$ ) and the association remained significant after the Bonferroni correction.

### **Care Partners' Fall Risk Management Support and Fall Outcomes among Community-dwelling OLWD by 12-month Fall History**

Table 3.4 summarizes the results of 168 logistic regressions with the dependent variables of fall outcomes (fall last year, multiple falls last year) by the history of falls (no fall, 1 fall, 2 or more). Each row of the table indicates statistically significant associations between the receipt of certain behaviors/domains of FRM support and OLWD's fall outcomes. None of these associations remain significant after correction for multiple comparisons via the Bonferroni method.

For the subgroup of OLWD who did not fall in 2015, accessing formal social care (OR=1.39; [1.03, 1.89],  $p=0.034$ ), especially use of paid care (OR=1.94; [1.16, 3.26],  $p=0.012$ ), was significantly associated with a higher risk of falls in the following year. For the subgroup of OLWD who only had one fall in 2015, the receipt of stability support was associated with a higher risk of falling (OR=4.03; [1.24, 13.07],  $p=0.021$ ) and a higher risk of multiple falls the following year (OR=4.44; [1.59, 12.39],  $p=0.005$ ). However, when members of this group had more care partners helping with medication management (OR=0.33, [0.13, 0.87],  $p=0.024$ ), wound care (OR=0.17, [0.02, 0.64],  $p=0.027$ ), participated in learning behaviors (OR=0.11; [0.02, 0.64],  $p=0.014$ ), and home safety modifications (OR=0.36; [0.14, 0.95],  $p=0.040$ ), their fall risk was lower. Care partners' efforts in wound care (OR=0.07, [0.01, 0.84],  $p=0.036$ ) and physical environment modification (OR=0.45, [0.22, 0.90],  $p=0.023$ ), especially the home safety modification (OR=0.16, [0.03, 0.91],  $p=0.039$ ), were also significantly associated with lower risk of multiple falling in the following year.

Table 3.4. Statistically significant associations between care partners' fall risk management support and fall outcomes among community-dwelling OLWD by history of falls <sup>a</sup>

| Sub-sample based on history of falls in 2015 | Fall risk management support (2015)                | Fall outcomes 2016       | OR (95%CI)        | P-value <sup>b</sup> |
|----------------------------------------------|----------------------------------------------------|--------------------------|-------------------|----------------------|
| Had no fall (n=206)                          | <b>Domain 6: Accessing formal social care</b>      | Fall last year           | 1.39 (1.03-1.89)  | 0.0335 *             |
|                                              | 6.1 Use of paid care                               |                          | 1.94 (1.16-3.26)  | 0.0121 *             |
| Had one fall (n=60)                          | 1.1 Stability support                              | Fall last year           | 4.03 (1.24-13.07) | 0.0205 *             |
|                                              | <b>Domain 3: Medication management</b>             |                          | 0.33 (0.13-0.87)  | 0.0241 *             |
|                                              | <b>Domain 4: Wound care</b>                        |                          | 0.17 (0.04-0.82)  | 0.0268 *             |
|                                              | <b>Domain 8: Learning</b>                          |                          | 0.11 (0.02-0.64)  | 0.0140 *             |
|                                              | 9.1 Home safety modification                       |                          | 0.36 (0.14-0.95)  | 0.0400 *             |
|                                              | 1.1 Stability support                              | Multiple falls last year | 4.44 (1.59-12.39) | 0.0045 *             |
|                                              | <b>Domain 4: Wound care</b>                        |                          | 0.07 (0.01-0.84)  | 0.0360 *             |
|                                              | <b>Domain 9: Physical environment modification</b> |                          | 0.45 (0.22-0.90)  | 0.0233 *             |
|                                              | 9.1 Home safety modification                       |                          | 0.16 (0.03-0.91)  | 0.0386 *             |
|                                              |                                                    |                          |                   |                      |
| Had two falls or more (n=79)                 | <b>Domain 6: Accessing formal social care</b>      | Fall last year           | 0.30 (0.12-0.76)  | 0.0107 *             |
|                                              | 6.1 Use of paid care                               |                          | 0.06 (0.01-0.56)  | 0.0134 *             |
|                                              | 6.2 Use of respite care                            |                          | 0.19 (0.05-0.72)  | 0.0146 *             |
|                                              | <b>Domain 6: Accessing formal social care</b>      | Multiple falls last year | 0.34 (0.17-0.66)  | 0.0016 *             |
|                                              | 6.1 Use of paid care                               |                          | 0.09 (0.02-0.52)  | 0.0068 **            |
|                                              | 6.2 Use of respite care                            |                          | 0.19 (0.07-0.52)  | 0.0014 **            |
|                                              | 10.2 Reducing recreation activities                |                          | 5.17 (1.26-21.16) | 0.0223 *             |

**Note:**

- Adjusted for variables race/ethnicity (n=360), education (n=356), pain (n=360), fear of falling (n=361), cognitive functions (n=331), number of chronic conditions (n=358), unmet needs in ADL (n=361), live alone (n=362).
- \*p<0.05, \*\*p<0.01, \*\*\*p<0.001; four digits after decimals of p-value were reported to allow for Bonferroni corrections. Bonferroni corrections on post hoc tests were used to assess the risk of type 1 error from repeated hypotheses by dividing the p-value by the number of tests: 0.05/420=0.0001.

For the subgroup who had two or more falls in 2015, their care partners' use of formal social care, including use of paid care and respite care, were associated with lower risk of falls (OR=0.30; [0.12, 0.76],  $p=0.011$ ) and multiple falls (OR=0.34; [0.17, 0.66],  $p=0.002$ ) in the following year. For this subgroup, care partner reduction of recreation activities was associated with higher risk of multiple falls for OLWD (OR=5.17; [1.26, 21.16],  $p=0.022$ ).

## **Discussion**

To my knowledge, this study was the first to examine the association between the receipt of care partners' FRM support and fall-related outcomes for OLWD based on a validated behavioral framework for care partners' FRM. This study also found varied associations between care partners' FRM and fall risk reduction by 12-month fall history.

### **Fall Risk Management Support Associated with OLWD's Higher Risk of Falling**

Adjusting for covariates, the receipt of certain FRM support, including stability assistance and care partners' work time and recreation activities reductions, was associated with a higher risk of falling. These associations remained significant in subgroup analysis for OLWD who had one fall and two falls or more in the last year. Functional mobility assistance was also significantly associated with more fear of falling for OLWD. These findings suggest that the receipt of care partners' mobility assistance and care partners' adjustment in their routine activities can indicate a high risk of falling for OLWD, which are factors that could be used for fall risk screening for community-dwelling OLWD. However, the mechanisms of this association are unclear. Previous studies suggest that care partners might notice OLWD's risk of falling by observing their

health conditions (Zhou, 2021a; Zhou et al., 2020). Some of these conditions that are observable by care partners are not included in the current analysis, including fatigue, spatial awareness, urinary tract infections, alcohol use, sensory loss, and OLWD's refusal to collaborate (Casey et al., 2020). It is possible that context not captured by NHATS data is informing care partners' FRM behaviors and that care partners are better attuned to the OLWD's fall risk. This may result in people with higher fall risk based on factors not captured in this study receiving greater support from care partners. Future research should explore the risk factors of falls from the perspectives of dementia care partners to better inform intervention development and clinical practice (Zhou et al., 2020).

These positive associations might also be because care partners lack the knowledge and skills to provide effective functional mobility assistance due to the complex mobility impairment experienced by OLWD (Oddy, 1987) and care partners' fear of falling (Ang et al., 2019, 2020; Shen et al., 2015). Previous studies suggested that care partners experience fall concerns and worry about OLWD falling at home, which was significantly associated with care partners' psychological distress, social restriction, and caregiving burden among care partners (Ang et al., 2019; Zhou et al., 2020). In a study of older adults experiencing a hip fracture, their care partners were more concerned about falls than were older adults (Shen et al., 2015). Care partners' fear of falling might result in a loss of confidence in older adults' balance and feeling the need to constantly provide assistance to them, which can inadvertently increase older adults' dependence (Honaker & Kretschmer, 2014). These findings reflect the complex relationships between care partners' functional mobility assistance, self-adjustment behaviors, and OLWD's risk of falling, which requires further exploration.



The possible mechanisms behind the positive association between medication management and OLWD's activity limitations due to fear of falling are also unclear. OLWD who need assistance in medication management might be prescribed multiple medications, which may increase the risk of non-adherence (Murray et al., 2004). Therefore, this association might be related to polypharmacy, especially polypharmacy of CNS-active medication (Casey et al., 2020). Anxiety and depression were common mental health conditions in this sample and were associated with fear of falling (Peeters et al., 2020) and the use of CNS-active medication (Choi et al., 2020; Ensrud, 2003). Care partners play an essential role in multiple medication management for OLWD (M. Lee et al., 2019). However, they often lack the training to manage medication effectively. They are particularly ill-equipped to manage the side effects of medications, such as sedentary behaviors or falls and fractures (Gillespie et al., 2014). This finding suggests the need for interventions to reduce fall risk associated with polypharmacy through engaging and educating care partners who are likely to be managing medication for OLWD.

Diet support and exercise support has been shown to be an effective FRM strategy among the general older adult population (Gillespie & Lamb, 2012; Smee et al., 2015). There were also limited evidence-based programs showing some positive impact of a nutrition program (Suominen et al., 2015) and an exercise program (Pitkälä et al., 2013) in fall risk reduction for community-dwelling OLWD. However, the study found that care partners' diet support and exercise support was associated with more fear of falling for OLWD, which highlights the need to take OLWD's fear of falling into consideration when engaging care partners to provide this support. To date, there are inconsistent findings about the associations between dementia and fear of falling. A few

studies have reported that persons living with Alzheimer's Disease, dementia with Lewy Bodies, and mild cognitive impairment had more concerns about falling than cognitively healthy subjects (Borges et al., 2015; Soysal et al., 2021). Another study suggested that cognitive impairment, especially in executive function, is associated with the absence of fear of falling (Shirooka et al., 2017). Given these mixed findings, future research should examine how care partners provide health promotion support, especially exercise and diet, and explore how this support relates to fear of falling for OLWD.

### **Fall Risk Management Support Associated with OLWD's Quality of Life**

Another finding of the study is that care partners accessing medical care and using support groups were significantly associated with OLWD's higher quality of life, including better self-reported physical health and reduced anxiety. These findings suggest that, although care partners' FRM behaviors might not effectively reduce fall risk in the following year, it might be beneficial for OLWD's quality of life. Prior studies suggest that care partners' expected benefits of managing fall risk extend beyond mitigating fall risk to include benefiting OLWD's overall physical and mental health (Zhou et al., 2020). Therefore, these behaviors might be critical to include in future interventions to engage care partners' in FRM.

The study found that care partners' adjustment in their routine activities might have varied associations with OLWD's quality of life. Their self-adjustment might be associated with higher physical activity participation for OLWD; however, it might also be associated with OLWD's higher report of depression. Previous studies suggest that a lack of self-care behaviors among dementia care partners negatively impacts care partners' stress and burden (Waligora et al., 2018). Although the reason why care partners' self-adjustment and OLWD's depression symptoms are associated is unclear,

these findings highlight that care partners' self-sacrifice might not always be beneficial to OLWD. The impact of care partners' self-adjustment in their routine activities on OLWD' health and well-being, especially OLWD's mental health, requires further exploration. As care partners often adopt these adjustments responding to OLWD's risk of falling (Zhou et al., 2020), care partners' need for self-care might be incorporated when engaging them to manage fall risk for OLWD.

### **Fall Risk Management Support Associated with OLWD's Lower Risk of Falling**

For full sample analysis, no FRM support was associated with lower risk of falling for OLWD. However, the study identified care partners' FRM support that is associated with lower risk of falling for OLWD who only had one fall in the last year, including care partners' medication management, wound care, learning, and physical environment modification. Overall, these findings highlight the importance of care partners' FRM efforts for OLWD who have a relatively low risk of falling.

There is a growing body of literature examining care partners' roles in medical and nursing tasks, typically thought of as under the purview of healthcare professionals, such as multiple medication management, skin wounds/sores care, and monitoring OLWD's medical conditions (M. Lee et al., 2019). Previous literature has focused on the challenges that care partners experience when managing those complex tasks, while there is limited examination of how these efforts might improve OLWD' health and well-being (M. Lee et al., 2019). The study demonstrates the possible contributions of care partners in fall risk reduction through taking on medical/nursing tasks, which highlight the importance of care partners receiving better-structured information, training, and support from healthcare professionals.

Another striking finding of the study is that care partners' learning behaviors may reduce fall risk for OLWD. Learning behaviors in this study included the use of support groups and receiving training. Previous studies emphasize the importance of learning in care partners' FRM, not only from professional care providers but also from life experiences and social networks (especially other care partners) (Zhou et al., 2021a). Support group services might also be a potential education opportunity to facilitate care partners' learning in FRM through their interactions with other care partners.

Another area that requires more detailed exploration is care partners' physical environment modification. Home safety modification (Struckmeyer & Pickens, 2015), assistive technology (Brims & Oliver, 2018), and mobility devices (Hunter, 2020) are often recommended as essential FRM strategies for OLWD. However, the substantial variation across different types of physical environment modifications might have varied impacts on fall risk among OLWD, and such associations might be moderated by older adults' mobility and risk-taking behaviors (Feldman & Chaudhury, 2008). To date, there is limited evidence of how care partners' support in physical environment modifications might impact OLWD's fall risk (Struckmeyer & Pickens, 2015). The findings from the study suggest the promising impact of care partners' efforts in this domain. Further research is needed to understand which types of physical environment modifications adopted by care partners are particularly effective in fall risk reduction, and how to strengthen care partners' engagement in those efforts in order to replicate them in research or clinical practice.

## **Fall Risk Management Support That Had Varied Associations with OLWD's Risk of Falling**

Another critical finding of this study is the varied associations between care partners' use of formal social care and OLWD's risk of falling. Care partners' use of paid care was associated with OLWD's higher risk of falling among those who had not fallen in the previous year, but it was associated with a lower risk of falling for OLWD who were at high risk of falling. Use of respite care was associated with a lower risk of falling for OLWD who had multiple falls in the last year. This finding partially aligns with a previous study that found the receipt of formal care was associated with reduced fall-related injury for older adults living with cognitive impairment and physical impairment (Hoffman et al., 2017). This finding suggests that even for OLWD who are currently at high risk of falling, enhancing access to formal social care for dementia care partners might still bring benefits to reduce the risk of falling for OLWD. This finding highlights the importance of avoiding fatalism that falls are universally part of "normal" aging and not preventable, and the need to shift the FRM paradigm from risk factor reduction to a more supportive approach (Casey et al., 2020).

However, it is unclear why the use of paid care was associated with a higher risk of falling among OLWD who had a lower fall risk. The use of paid care is likely driven not only by OLWD's functional need but also socioeconomic status (such as income or Medicaid status) and the caregiving context (e.g., living arrangements and availability of care partners) (Reckrey, Morrison, et al., 2020). This study finding suggests that the use of paid care does not necessarily mean OLWD's care needs are met. Instead, using formal social care needs to be examined in the context of overall care and support received by OLWD, functional need, and other potential socioeconomic factors that might be associated with a high risk of falling, such as availability and caregiving time of

informal care partners (Hoffman et al., 2017), quality of paid care (Alzheimer's Association, 2021), OLWD's education level (Hoffman et al., 2017), income (Marshall et al., 2005), and home and neighborhood environment (Chippendale & Boltz, 2015; Wing et al., 2017). When engaging care partners in FRM, it may be important to address different roles of paid care at different stages of FRM.

### **Fall Risk Management Support that Had no Significant Associations with OLWD's Risk of Falling**

No significant associations were observed between OLWD's risk of falling and care partners' accessing medical care and use of informal care. The insignificant finding suggests the need to strengthen FRM for OLWD in primary care settings (Hoffman et al., 2018), which highlights the importance of the collaborations between care partners and healthcare providers in addressing the healthcare needs of OLWD during clinical encounters (Griffin et al., 2019; Sadak et al., 2015).

The use of informal care has been described as an important strategy for care partners' FRM, especially when care partners are not present, when they discuss OLWD's health conditions with other care partners, and when they prepare for older adults' emergency needs (Zhou, 2021a). However, there are substantial differences between FRM support provided by different care partners (Zhou, 2021b). Therefore, more appropriate measures are needed to capture the care networks' collective and varied engagement in FRM.

### **Limitations**

This study has several limitations. Proxies reporting on behalf of OLWD may not accurately report their health conditions and fall-related outcomes. Due to data limitations, the study was not able to examine 16 FRM behaviors that are included in the

behavioral framework of dementia care partners' FRM (Zhou, 2021a). FRM behaviors included were operationalized using NSOC as binary variable and based on care partners' self-report. These measures might not be able to accurately reflect care partners' heterogeneous experiences in FRM. This study was also not able to assess how these behaviors were associated with fall injuries, fall-related self-efficacy, and the specific number of falls more than 2 that are suggested by the fall-related outcome framework (Lamb et al., 2005). Due to the limitation of the sample size, the study was not able to examine the associations between OLWD's fall risk among American Indian, Asian, Native Hawaiian communities.

Another limitation is missing outcomes due to participants moving to residential settings and mortality. This missing outcome data might be because of these competing risks of residential setting placement and mortality - these two events occur competing with the fall-related outcomes; these events hinder the observation of the fall-related outcomes in the community settings or modifies the chance that fall-related outcomes occur (Noordzij et al., 2013; Staffa & Zurakowski, 2019). Although the fall-related outcome framework of the study suggested 12 months as the time point for follow-up (Lamb et al., 2005), it might not be enough to capture the impact of some FRM support. Therefore, longitudinal analyses over a longer period of time and the analysis of competing risks should be considered for future research.

For the sub-group analysis, the small sample size of each sub-group and multiple comparison issues increases the risk of false positives (Bujang et al., 2018; Supplee et al., 2013). Future research should further examine the care partners' behaviors that showed promising benefits in fall risk reduction using larger sample size.

## **Conclusion**

This study addresses important evidence gaps regarding the complex associations between receipt of care partners' FRM support and fall-related outcomes among community-dwelling OLWD. These findings highlighted the promising benefits of care partners' medication management, wound care, learning behaviors, accessing formal social care, and physical environment modification in fall risk reduction for community-dwelling OLWD, although these findings require further examination and validation. The study also found that certain FRM behaviors, including functional mobility assistance, health promotion support, and medication management might be associated with a higher risk of falling for OLWD. These findings have important implications for future research. To develop interventions to engage care partners' roles in FRM, future research should further explore:

- the complex relationships between care partners' fear of falling, functional mobility assistance, self-adjustment behaviors, and OLWD's risk of falling,
- care partners' roles in address polypharmacy of CNS-active medication for OLWD,
- associations between care partners' health promotions efforts and OLWD's fear of falling,
- how care partners' self-adjustment behaviors impact OLWD's health outcomes, especially mental health,
- different roles of paid care at different stages of FRM for OLWD,
- how to reduce fall risk for community-dwelling OLWD through enhancing care partners' medication management, wound care, learning, and physical environment modifications behaviors,



- how primary care settings are working with dementia care partners in managing fall risk for OLWD,
- how to develop and validate measures to capture the informal care networks' collective and varied engagement in FRM, and
- the long-term impact of care partners' efforts on fall risk reduction.

Our findings suggest several practice implications. First, new interventions are needed that incorporate care partners' concerns, needs, and experiences of OLWD's risk of falling and engage care partners in addressing polypharmacy of CNS-active medication that might increase OLWD's risk of falling. Second, future interventions should pay attention to OLWD's fall history to learn if it is helpful to adjust interventions for care partners of OLWD with different fall histories. For example, early interventions that target care partners' medication management, wound care, learning behaviors, and physical environment modifications might be beneficial to effectively manage OLWD's risk of falling. Interventions that aim to enhance care partners' access to formal social care might also need to consider OLWD's fall history, overall care arrangement, and socioeconomic status that might impact OLWD's risk of falling.

Primary care settings lack effective strategies to manage fall risk for older adults, especially for OLWD (Hoffman et al., 2018; Tan et al., 2020). Since care partners are important liaisons between OLWD, community-based organizations, and healthcare systems, practitioners and policymakers should develop strategies to strengthen the partnership between primary care settings and dementia care partners in reporting, screening, assessing, and addressing OLWD's risk of falling.

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Zhou, Y. (2021a). Dementia care partners' fall risk management: Developing a behavioral framework using a grounded theory approach. Dissertation paper 1.

Zhou, Y. (2021b). Validation of a behavioral framework for dementia care partners' fall risk management. Dissertation paper 2.

## **CONCLUSION**

This three-paper dissertation develops and validates a behavioral framework for dementia care partners' fall risk management (FRM) and examines the associations between care partners' FRM behaviors and fall-related outcomes for community-dwelling OLWD. It contributes to the fields of social work and interprofessional care practices (geriatrics, public health, nursing, occupational therapy, physical therapy) by enhancing our understanding of care partners' engagement in managing fall risk for community-dwelling OLWD and by identifying possible connections between care partners' care activities and OLWD's fall-related outcomes.

The first paper proposes a behavioral framework for dementia care partners' FRM and identifies eight domains of dementia care partners' FRM behaviors (1. functional mobility assistance, 2. assessing and addressing health conditions, 3. health promotions support, 4. safety supervision, 5. physical environment modification, 6. receiving, seeking, and coordinating care, 7. learning, and 8. self-adjustment) across four stages of FRM (1. providing support before dementia diagnosis, 2. preventing falls, 3. preparing to respond to falls, and 4. responding to falls). This study also reveals differences between primary and secondary care partners and intentional and unintentional FRM. The framework presents different possible mechanisms and processes through which care partners can impact fall risk among community-dwelling OLWD.

To validate this framework, the second paper examines the prevalence and dimensionality of FRM behaviors, and differences between primary and secondary care partners utilizing the National Health and Aging Trends Study (NHATS) 2015 and the National Study of Caregiving (NSOC) 2015, two linked national surveys. This study finds

that some FRM behaviors are more prevalent than others, which suggests different opportunities for intervention development to engage dementia care partners in a broader range of behaviors. The study validates five domains of FRM proposed in the first paper (1. functional mobility assistance, 2. physical environment modification, 3. health promotion support, 4. learning, and 5. self-adjustment), identifies the associations among medication management, health promotion, and accessing medical services, and the complexity of “receiving, seeking, and coordinating care”, which is broken down into the following three domains of FRM behaviors: accessing medical care, accessing formal social care, and use of informal care.

Findings from this study reveal different behavioral patterns between primary and secondary care partners in FRM. Primary care partners provide more types of instrumental activities of daily living, such as diet support, medication, wound care, and the use of medical care. However, there were no significant differences between primary and secondary care partners in some other types of FRM behaviors, especially functional mobility assistance, physical environment modification, learning, and the use of formal social care. Primary care partners also have more comprehensive care activity involvement. Secondary care partners might have more specialization or a specific role in providing support in certain aspects of care and may have a greater variation in the level of support they provide.

This second study modifies and validates the behavioral framework that can be used to inform future research to examine the impact of care partners’ engagement in FRM on fall-related outcomes among community-dwelling OLWD, and how to engage dementia care partners in FRM considering their heterogeneous experiences.

Informed by this validated framework, the third paper focuses on assessing fall risk reduction for community-dwelling OLWD associated with receipt of FRM support from their care partners. This study findings highlight the importance of care partners' medication management, wound care, learning behaviors, accessing formal social care, and physical environment modification in potentially reducing the risk of falling for community-dwelling OLWD. The study also finds that certain FRM behaviors, including functional mobility assistance, health promotion support, and medication management might be associated with a higher risk of falling for OLWD. This research has important implications for future research about these FRM behaviors and suggests the need for adjusting interventions for dementia care partners based on OLWD's fall history. This paper highlights the need to enhance the partnership between primary care settings and dementia care partners in FRM.

Overall, the findings from this dissertation yield contribution to both practice and health and social-behavior science inquiry. My study addresses the need for a behavioral framework to understand care partners' FRM behaviors and assess the contributions and limitations of care partners. It also generates understandings of the areas where care partners may have contributions and areas that they may need more training and support. Such targeted training may address the need to develop effective partnerships between care partners and social and health care providers in managing FRM. As falls are the leading cause of nonfatal and fatal injuries (Bergen, 2016), and fall-related injuries are a leading cause of emergency department visits and hospitalizations among older adults (Benner et al., 2016), these endeavors would help reduce the negative outcomes for the healthcare systems and strengthen older adults' capacity to age in place.

Healthy aging and managing health risk have often been conceptualized as an individual responsibility to stay active and healthy (Katz, 2011; Morden et al., 2012). Caregiving for older adults and those with chronic illnesses/disabilities have often been conceptualized as the responsibilities of family members (Bell et al., 2019; Buhler-Wilkerson, 2007; Hooyman & Gonyea, 1999). This distribution of caring responsibilities for OLWD does not align with the principle of social justice and the public ethics of care. A public ethic of care has been described as an ethic that “locate the responsibility for care in the public sphere where the work of care is assigned value because it is a public good and a demanding, skilled activity that can be done well or poorly, and it matters that it be done well (Berridge, 2012)”. However, in the United States, despite growing interests in support OLWD to age in place, policies have limited support to address the major long-term care need for the aging population, such as home health care and social services (Hooyman & Gonyea, 1999; Howard et al., 2019; Talley & Crews, 2007). Informal care partners provide the majority of long-term services and support (Doty & Spillman, 2015) and both their contributions and limitations in managing complex health risks associated with aging and dementia go overlooked (Quiñones et al., 2020). Furthermore, these challenges are disproportionately impacting underserved populations (Harrison et al., 2019).

These demanding and frequently long-term responsibilities not only bring financial stressors and changes to care partners’ social life and employment conditions, but also bring negative impact on their life satisfaction, physical and mental health, and mortality (Zhou et al., 2020). Approximately two-thirds of dementia care partners worldwide, including the United States, are women. The increasing care needs of OLWD and insufficient support for dementia care partners might exacerbate the gender and

economic inequalities due to the unequal responsibilities of care work (Alzheimer's Society, 2020; Coffey et al., 2020). The complex medical needs of OLWD are associated with higher care burdens and emotional difficulties for dementia care partners (Alzheimer's Society, 2020; Leggett et al., 2018; Polenick et al., 2017). Therefore, there is an urgent need in developing evidence-based interventions and policies to recognize and support informal care partners of OLWD (Bell et al., 2019; Reyes et al., 2021).

This dissertation challenges the dominant assumption of personal responsibility of healthy aging. It reveals family and friends' significant responsibilities and contributions to social and healthcare systems through FRM for OLWD, as well as limitations of care partners' capacity in managing complex health conditions. Therefore, these findings identify opportunities for formal care systems to recognize, support, and supplement care partners' existing efforts.

This dissertation research has the following implications for the social work profession. Social workers play central roles in engaging and working with care partners to manage the health and well-being of community-dwelling OLWD (Kaplan & Berkman, 2011). The research findings may help us move towards the development of assessment tools or applied interventions for social workers to work with care partners, community public health practitioners, community nurses, and primary care providers in managing fall risk for OLWD. Social workers can be positioned to strengthen care partners' effective FRM behaviors or reduce ineffective or harmful FRM behaviors using their professional skills in working with individuals, families, communities, and care systems. Future social work research on dementia caregiving and FRM should continue to contribute to our understanding of how personal, interpersonal, and societal factors facilitate or hinder dementia care partners' efforts in FRM, especially those from

underserved communities. With this knowledge, social workers can enhance current primary care and home and community-based services for OLWD and empower care partners to manage the health and well-being of OLWD and themselves.

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## APPENDIX

### Appendix 2.1. Survey questions from 2015 NSOC

| Proposed fall risk management behaviors (Dissertation paper 1)            | Fall Risk Management Behaviors      | Item in 2015 NSOC                | Survey questions                                                                                                                                                                                                                               |
|---------------------------------------------------------------------------|-------------------------------------|----------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Domain 1: Functional mobility assistance                                  |                                     |                                  |                                                                                                                                                                                                                                                |
| Walking assistance                                                        | 1.1 Stability support               | C5 CA8C HOLD STEADY WHILE WALK   | {[] } In the last month, when you helped {SP} with personal care, did you ever...{[] } RESPONSE [3] c. hold {him/her} steady while {he/she} walked or stood?                                                                                   |
| Standing assistance                                                       | 1.2 Weight support                  | C5 CA8B LEANED ON OR SUPPRT WGHT | {[] } In the last month, when you helped {SP} with personal care, did you ever...{[] }RESPONSE [2] b. let {him/her}lean on you or support{his/her} weight?                                                                                     |
| Toileting assistance<br><br>Shower/bath assistance<br><br>Hazard reminder | 1.3 Activity support                | C5 CA7 HOW OFT HLP GTNG ARD HOME | In the last month, how often did you help {SP} get around, that is, getting in and out of bed, getting around inside {his/her} home, or leaving {his/her} home to go outside? Would you say every day, most days, some days, rarely, or never? |
| Mobility restraint                                                        | No relevant survey questions (NRSQ) |                                  |                                                                                                                                                                                                                                                |
| Domain 2: Assessing and addressing health conditions                      |                                     |                                  |                                                                                                                                                                                                                                                |
| Medication management                                                     | 2.1 Medication management           | C5 CA11A KEEP TRACK OF MEDS      | {[] } In the last month, did you ever help {SP}...{[] } a. keep track of {his/her} medications?                                                                                                                                                |
| Address physical and mental health conditions                             | 2.2 Wound care                      | C5 CA11H HELP W SKIN CARE WOUNDS | {[] } In the last month, did you ever help {SP}...{[] } h. with skin care related to wounds or sores?                                                                                                                                          |
| Assess physical and mental health conditions                              | NRSQ <sup>a</sup>                   |                                  |                                                                                                                                                                                                                                                |
| Domain 3: Safety supervision                                              |                                     |                                  |                                                                                                                                                                                                                                                |
| Pay close attention                                                       | NRSQ                                |                                  |                                                                                                                                                                                                                                                |
| Regular check-in                                                          | NRSQ                                |                                  |                                                                                                                                                                                                                                                |
| Be present                                                                | NRSQ                                |                                  |                                                                                                                                                                                                                                                |
| Domain 4: Physical environment modification                               |                                     |                                  |                                                                                                                                                                                                                                                |

## Appendix 2.1. Continued.

|                                                            |                              |                                   |                                                                                                                                                                                                                                        |
|------------------------------------------------------------|------------------------------|-----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Home safety assessment, modification, and organizing       | 3.1 Home safety modification | C5 SE11 MADE SP HOME SAFER        | In the last year, have you {made your home safer for {SP}/helped {SP} make {his/her} home safer} by adding features such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system? |
| Support use of monitoring technology                       |                              |                                   |                                                                                                                                                                                                                                        |
| Support use of mobility assistive technology               | 3.2 Use of mobility devices  | C5 SE10 HLPD GET MOBILITY DEVICES | In the last year, have you helped {SP} to get devices to get around more easily, such as a cane, walker, wheelchair, or scooter                                                                                                        |
| Ensure the safety of shoes/socks                           | NRSQ                         |                                   |                                                                                                                                                                                                                                        |
| <b>Domain 5: Health promotion support</b>                  |                              |                                   |                                                                                                                                                                                                                                        |
| Diet support                                               | 4.1 Diet support             | C5 CA11E HELP WITH A SPECIAL DIET | {[]} In the last month, did you ever help {SP}...{[]} ] e. with a special diet?                                                                                                                                                        |
| Exercise support                                           | 4.2 Exercise support         | C5 CA11D HELP WITH EXERCISES      | {[]} In the last month, did you ever help {SP}...{[]} d. with exercises {he/she} was supposed to do?                                                                                                                                   |
| Health and risk communication                              | NRSQ                         |                                   |                                                                                                                                                                                                                                        |
| Enhance activity engagement                                | NRSQ                         |                                   |                                                                                                                                                                                                                                        |
| Improve and maintain self-efficacy                         | NRSQ                         |                                   |                                                                                                                                                                                                                                        |
| Improve help-seeking behaviors                             | NRSQ                         |                                   |                                                                                                                                                                                                                                        |
| <b>Domain 6: Receiving, seeking, and coordinating care</b> |                              |                                   |                                                                                                                                                                                                                                        |
| Hire and coordinate with paid caregivers                   | 5.1 Use of paid care         | C5 SE12 HELPED FIND PAID HELPER   | In the last year, have you helped {SP} find a paid helper to do household chores or personal care?                                                                                                                                     |
| Use of informal care                                       | 5.2 Use of informal care     | C5 SE3 FRIENDS FAMILY HELP W SP   | Do you have friends or family that help you care for {SP}?                                                                                                                                                                             |
| Use of social and health services                          | 5.3 Use of respite care      | C5 SE4A USED SERV TAKE TIME AWAY  | In the last year, have you used any service that took care of {SP} so that you could take some time away from helping?                                                                                                                 |
|                                                            | 5.4 Medical appointment      | C5 CA12A HELP MAKE MEDICAL APPTS  | {[]} In the last year, did you ever...{[]} . make appointments for {SP} with a medical provider?                                                                                                                                       |
| Communicate with other care partners and professionals     | 5.5 Medical communication    | C5 CA12B HLP SPEAK TO MED PROVDR  | {[]} In the last year, did you ever...{[]} ] b. speak to or e-mail {SP}'s medical provider about {his/her} care?                                                                                                                       |



## Appendix 2.1. Continued.

|                                            |                                    |                               |                                                                                                                                                        |
|--------------------------------------------|------------------------------------|-------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Domain 7: Learning</b>                  |                                    |                               |                                                                                                                                                        |
| Learn from social network                  | 6.1 Use of support groups          | C5 SE4 GONE TO SUPPORT GROUP  | In the last year, have you gone to a support group for people who give care?                                                                           |
| Learn from professionals                   | 6.2 Receiving training             | C5 SE5 U RCVD TRAINING 2 HELP | In the last year, have you received any training to help you take care of {SP}?                                                                        |
| Learn from care partners' life experiences | NRSQ                               |                               |                                                                                                                                                        |
| Learn from older adults with dementia      | NRSQ                               |                               |                                                                                                                                                        |
| Learn from media and internet              | NRSQ                               |                               |                                                                                                                                                        |
| <b>Domain 8: Self-adjustment</b>           |                                    |                               |                                                                                                                                                        |
| Avoid social activities                    | 7.1 Reducing family activities     | C5 PP2 KEPT FRM VISITING      | In the last month, did helping {SP} ever keep you from doing this (visiting in person with friends or family not living with you)?                     |
|                                            | 7.2 Reducing recreation activities | C5 PP11 KEPT FRM GOING OUT    | In the last month, did helping {SP} ever keep you from doing this (going out for enjoyment)?                                                           |
|                                            | 7.3 Reducing religious activities  | C5 PP5 KEPT FRM RELIG SERV    | In the last month, did helping {SP} ever keep you from doing this (attending religious services)?                                                      |
|                                            | 7.4 Reducing group activities      | C5 PP8 KEPT FRM GROUP ACTIV   | In the last month, did helping {SP} ever keep you from doing this (participating in club meetings or group activities {other than religious services}) |
| Reducing working time                      | 7.5 Reducing work time             | C5 PP14 KEPT FRM WORKING      | STION TEXT: In the last month, did helping {SP} ever keep you from doing this (working for pay)?                                                       |
| Change living arrangement                  | NRSQ                               |                               |                                                                                                                                                        |
| Change sleeping arrangement                | NRSQ                               |                               |                                                                                                                                                        |
| Adapt walking behaviors                    | NRSQ                               |                               |                                                                                                                                                        |

*Note:* NRSQ represent no relevant survey questions.

## Appendix 2.2. Results from exploratory factor analysis under the item response theory

| Model               | AIC             | AICc            | SABIC           | BIC             | LogL        | Models |              |             |       |
|---------------------|-----------------|-----------------|-----------------|-----------------|-------------|--------|--------------|-------------|-------|
| 1                   | 13691.46        | 13695.05        | 13744.83        | 13859.15        | -6809.731   |        | $\Delta X^2$ | $\Delta df$ | p     |
| 2                   | 13318.68        | 13326.58        | 13397.26        | 13565.56        | -6606.342   | 1 vs 2 | 406.779      | 17          | 0     |
| 3                   | 13153.83        | 13167.46        | 13256.13        | 13475.24        | -6507.918   | 2 vs 3 | 196.848      | 16          | 0     |
| 4                   | 13063.01        | 13083.59        | 13187.54        | <b>13454.28</b> | -6447.505   | 3 vs 4 | 120.826      | 15          | 0     |
| 5                   | 13012.61        | <b>13041.14</b> | <b>13157.90</b> | 13469.09        | -6408.304   | 4 vs 5 | 78.401       | 14          | 0     |
| 6                   | 13014.70        | 13051.98        | 13179.26        | 13531.74        | -6396.351   | 5 vs 6 | 23.906       | 13          | 0.032 |
| 7                   | <b>13001.44</b> | 13048.02        | 13183.80        | 13574.38        | -6377.722   | 6 vs 7 | 37.258       | 12          | 0     |
| 8                   | 13028.48        | 13084.66        | 13227.14        | 13652.66        | -6380.242   | 7 vs 8 | -5.039       | 11          | 1     |
| M <sub>2</sub> test | M <sub>2</sub>  | df              | p               | RMSEA           | 0.9CI       | SRMSR  | TLI          | CFI         |       |
| 4                   | 234.7459        | 87              | 0.000           | 0.047           | 0.040-0.054 | 0.037  | 0.945        | 0.969       |       |
| 5                   | 136.167         | 73              | 0.000           | 0.033           | 0.025-0.042 | 0.030  | 0.971        | 0.987       |       |
| 7                   | 63.760          | 87              | 0.063           | 0.021           | 0-0.033     | 0.021  | 0.989        | 0.996       |       |

### Note:

- LogL, log-likelihood; AIC, Akaike information criterion; AICc, corrected AIC; BIC, Bayesian information criterion; SABIC, Sample-Size Adjusted BIC. The number of the model corresponds to the number of dimensions.
- Bolded numbers of different information criteria were the smallest ones across all the eight models, which suggest better fit. For M<sub>2</sub> test, p<0.05 were considered to show misfit; for the RMSEA and SRMR, values ≤ 0.05 ideal and values ≤ 0.08 were considered acceptable; for the CFI and TLI, values ≥ 0.95 ideal and ≥ 0.90 considered acceptable (Cai & Hansen, 2013). (Cai, L., & Hansen, M. (2013). Limited-information goodness-of-fit testing of hierarchical item factor models. *British Journal of Mathematical and Statistical Psychology*, 66(2), 245–276. <https://doi.org/10.1111/j.2044-8317.2012.02050.x>)

Appendix 2.3. Model selections using subsamples of primary and secondary care partners (CP)

| Prim<br>ary<br>CP      | AIC            | AICc           | SABIC           | BIC            | LogL        | Models | ΔX2     | Δdf   | p            |
|------------------------|----------------|----------------|-----------------|----------------|-------------|--------|---------|-------|--------------|
| 1                      | 8192.892       | 8197.595       | 8225.021        | 8326.586       | -4064.446   |        |         |       |              |
| 2                      | 7966.008       | 7976.405       | 8013.198        | 8162.372       | -3936.004   | 1 vs 2 | 256.883 | 15    | 0            |
| 3                      | 7895.581       | 7913.591       | 7956.827        | <b>8150.44</b> | -3886.791   | 2 vs 3 | 98.427  | 14    | 0            |
| 4                      | 7854.374       | 7881.647       | 7928.672        | 8163.542       | -3853.187   | 3 vs 4 | 67.207  | 13    | 0            |
| 5                      | <b>7826.39</b> | 7864.268       | <b>7912.731</b> | 8185.688       | -3827.192   | 4 vs 5 | 51.989  | 12    | 0            |
| 6                      | 7828.693       | 7878.204       | 7926.084        | 8233.954       | -3817.347   | 5 vs 6 | 19.691  | 11    | <b>0.050</b> |
| 7                      | 7843.754       | 7905.551       | 7951.186        | 8290.794       | -3814.877   | 6 vs 7 | 4.939   | 10    | 0.895        |
| 8                      | 7859.522       | 7933.890       | 7975.990        | 8344.164       | -3813.761   | 7 vs 8 | 2.232   | 9     | 0.987        |
| M <sub>2</sub><br>test | M <sub>2</sub> | df             | p               | RMSEA          | 90%CI       | SRMSR  | TLI     | CFI   |              |
| 3                      | 218.084        | 75             | 0.000           | 0.063          | 0.053-0.073 | 0.052  | 0.910   | 0.943 |              |
| 5                      | 85.225         | 50             | 0.001           | 0.038          | 0.024       | 0.052  | 0.967   | 0.986 |              |
| 6                      | 35.362         | 39             | 0.637           | 0              | 0-0.027     | 0.027  | 1.003   | 1     |              |
| Seco<br>ndar<br>y CP   | AIC            | AICc           | SABIC           | BIC            | LogL        | Models | ΔX2     | Δdf   | p            |
| 1                      | 4003.752       | 4017.344       | 4013.887        | 4127.989       | -1965.876   |        |         |       |              |
| 2                      | 3917.156       | 3949.133       | 3932.077        | 4100.061       | -1905.578   | 1 vs 2 | 120.596 | 17    | 0            |
| 3                      | 3852.209       | 3911.473       | 3871.634        | <b>4090.33</b> | -1857.104   | 2 vs 3 | 96.947  | 16    | 0            |
| 4                      | <b>3811.08</b> | <b>3907.56</b> | <b>3834.73</b>  | 4100.964       | -1821.538   | 3 vs 4 | 71.133  | 15    | <b>0</b>     |
| 5                      | 3820.08<br>0   | 3964.886       | 3847.670        | 4158.281       | -1812.040   | 4 vs 5 | 18.997  | 14    | 0.165        |
| 6                      | 3834.648       | 4040.135       | 3865.898        | 4217.713       | -1806.324   | 6 vs 5 | 11.432  | 13    | 0.575        |
| 7                      | 3861.681       | 4141.534       | 3896.310        | 4286.159       | -1807.841   | 6 vs 7 | -3.034  | 12    | 1            |
| 8                      | 3872.103       | 4241.287       | 3909.828        | 4334.542       | -1802.051   | 7 vs 8 | 11.578  | 11    | 0.396        |
| M <sub>2</sub><br>test | M <sub>2</sub> | df             | p               | RMSEA          | 90%CI       | SRMSR  | TLI     | CFI   |              |
| 3                      | 185.817        | 102            | 0.000           | 0.060          | 0.046-0.073 | 0.059  | 0.914   | 0.943 |              |
| 4                      | 72.248         | 73             | 0.503           | 0              | 0-0.037     | 0.039  | 1.002   | 1     |              |

Note:

- LogL, log-likelihood; AIC, Akaike information criterion; AICc, corrected AIC; BIC, Bayesian information criterion; SABIC, Sample-Size Adjusted BIC. The number of the model corresponds to the number of dimensions.
- For primary care partners, use of informal care, wound care, medication management, and learning (including use of support groups and receiving training) were removed for generating this model.
- For secondary care partners, use of informal care, wound care, and diet support were removed for generating this model.
- Bolded numbers of different information criteria were the smallest ones across all the eight models, which suggest better fit. For M2 test,  $p < 0.05$  were considered to show misfit; for the RMSEA and SRMR, values  $\leq 0.05$  ideal and values  $\leq 0.08$  were considered acceptable; for the CFI and TLI, values  $\geq 0.95$  ideal and  $\geq 0.90$  considered acceptable (Cai & Hansen, 2013). (Cai, L., & Hansen, M. (2013). Limited-information goodness-of-fit testing of hierarchical item factor models. *British Journal of Mathematical and Statistical Psychology*, 66(2), 245–276. <https://doi.org/10.1111/j.2044-8317.2012.02050.x>)

## Appendix 3.1. Survey questions from 2015 NSOC

| Fall Risk Management Behaviors                  | Item in 2015 NSOC                 | Survey questions                                                                                                                                                                                                                               |
|-------------------------------------------------|-----------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Domain 1: Functional mobility assistance</b> |                                   |                                                                                                                                                                                                                                                |
| 1.1 Stability support                           | C5 CA8C HOLD STEADY WHILE WALK    | {[]} In the last month, when you helped {SP} with personal care, did you ever...{[]} RESPONSE [3] c. hold {him/her} steady while {he/she} walked or stood?                                                                                     |
| 1.2 Weight support                              | C5 CA8B LEANED ON OR SUPPRT WGHT  | {[]} In the last month, when you helped {SP} with personal care, did you ever...{[]}RESPONSE [2] b. let {him/her}lean on you or support{his/her} weight?                                                                                       |
| 1.3 Activity support                            | C5 CA7 HOW OFT HLP GTNG ARD HOME  | In the last month, how often did you help {SP} get around, that is, getting in and out of bed, getting around inside {his/her} home, or leaving {his/her} home to go outside? Would you say every day, most days, some days, rarely, or never? |
| <b>Domain 2: Health promotion support</b>       |                                   |                                                                                                                                                                                                                                                |
| 2.1 Diet support                                | C5 CA11E HELP WITH A SPECIAL DIET | {[]} In the last month, did you ever help {SP}...{[]} ] e. with a special diet?                                                                                                                                                                |
| 2.2 Exercise support                            | C5 CA11D HELP WITH EXERCISES      | {[]} In the last month, did you ever help {SP}...{[]} d. with exercises {he/she} was supposed to do?                                                                                                                                           |
| <b>Domain 3: Medication management</b>          |                                   |                                                                                                                                                                                                                                                |
| 3.1 Medication management                       | C5 CA11A KEEP TRACK OF MEDS       | {[]} In the last month, did you ever help {SP}...{[]} a. keep track of {his/her} medications?                                                                                                                                                  |
| <b>Domain 4: Wound care</b>                     |                                   |                                                                                                                                                                                                                                                |
| 4.1 Wound care                                  | C5 CA11H HELP W SKIN CARE WOUNDS  | {[]} In the last month, did you ever help {SP}...{[]} h. with skin care related to wounds or sores?                                                                                                                                            |
| <b>Domain 5: Accessing medical care</b>         |                                   |                                                                                                                                                                                                                                                |
| 5.1 Medical appointment                         | C5 CA12A HELP MAKE MEDICAL APPTS  | {[]} In the last year, did you ever...{[]} . make appointments for {SP} with a medical provider?                                                                                                                                               |
| 5.2 Medical communication                       | C5 CA12B HLP SPEAK TO MED PROVDR  | {[]} In the last year, did you ever...{[]} ] b. speak to or e-mail {SP}'s medical provider about {his/her} care?                                                                                                                               |
| <b>Domain 6: Use of formal social care</b>      |                                   |                                                                                                                                                                                                                                                |
| 6.1 Use of paid care                            | C5 SE12 HELPED FIND PAID HELPER   | In the last year, have you helped {SP} find a paid helper to do household chores or personal care?                                                                                                                                             |
| 6.3 Use of respite care                         | C5 SE4A USED SERV TAKE TIME AWAY  | In the last year, have you used any service that took care of {SP} so that you could take some time away from helping?                                                                                                                         |
| <b>Domain 7: Use of informal care</b>           |                                   |                                                                                                                                                                                                                                                |

### Appendix 3.1. Continued.

|                                                    |                                   |                                                                                                                                                                                                                                        |
|----------------------------------------------------|-----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 7.1 Use of informal care                           | C5 SE3 FRIENDS FAMILY HELP W SP   | Do you have friends or family that help you care for {SP}?                                                                                                                                                                             |
| <b>Domain 6: Learning</b>                          |                                   |                                                                                                                                                                                                                                        |
| 8.1 Use of support groups                          | C5 SE4 GONE TO SUPPORT GROUP      | In the last year, have you gone to a support group for people who give care?                                                                                                                                                           |
| 8.2 Receiving training                             | C5 SE5 U RCVD TRAINING 2 HELP     | In the last year, have you received any training to help you take care of {SP}?                                                                                                                                                        |
| <b>Domain 9: Physical environment modification</b> |                                   |                                                                                                                                                                                                                                        |
| 9.1 Home safety modification                       | C5 SE11 MADE SP HOME SAFER        | In the last year, have you {made your home safer for {SP}/helped {SP} make {his/her} home safer} by adding features such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system? |
| 9.2 Use of mobility devices                        | C5 SE10 HLPD GET MOBILITY DEVICES | In the last year, have you helped {SP} to get devices to get around more easily, such as a cane, walker, wheelchair, or scooter                                                                                                        |
| <b>Domain 7: Self-adjusting</b>                    |                                   |                                                                                                                                                                                                                                        |
| 10.1 Reducing family activities                    | C5 PP2 KEPT FRM VISITING          | In the last month, did helping {SP} ever keep you from doing this (visiting in person with friends or family not living with you)?                                                                                                     |
| 10.2 Reducing recreation activities                | C5 PP11 KEPT FRM GOING OUT        | In the last month, did helping {SP} ever keep you from doing this (going out for enjoyment)?                                                                                                                                           |
| 10.3 Reducing religious activities                 | C5 PP5 KEPT FRM RELIG SERV        | In the last month, did helping {SP} ever keep you from doing this (attending religious services)?                                                                                                                                      |
| 10.4 Reducing group activities                     | C5 PP8 KEPT FRM GROUP ACTIV       | In the last month, did helping {SP} ever keep you from doing this (participating in club meetings or group activities {other than religious services})                                                                                 |
| 10.5 Reducing work time                            | C5 PP14 KEPT FRM WORKING          | STION TEXT: In the last month, did helping {SP} ever keep you from doing this (working for pay)?                                                                                                                                       |

## Appendix 3.2. Bivariate analysis for selecting covariates

|                                         |                                          | Fall last year<br>OR (95%CI)     | Multiple falls last year<br>OR (95%CI) |
|-----------------------------------------|------------------------------------------|----------------------------------|----------------------------------------|
| <b>Sociodemographic characteristics</b> | <b>Age</b>                               | 0.978 (0.94-1.01), p=0.187       | 0.98 (0.94-1.01), p=0.210              |
|                                         | <b>Female</b>                            | 0.80 (0.47-1.36), p=0.418        | <b>0.62 (0.36-1.10), p=0.100</b>       |
|                                         | <b>Race/ethnicity</b>                    |                                  |                                        |
|                                         | Non-Hispanic White                       | -                                | -                                      |
|                                         | Non-Hispanic Black                       | <b>0.46 (0.27-0.79), p=0.005</b> | <b>0.33 (0.17-0.66), p=0.002</b>       |
|                                         | Hispanic                                 | 0.48 (0.21-1.12), p=0.092        | 0.59 (0.24-1.40), p=0.228              |
|                                         | Other                                    | 0.59 (0.16-2.16), p=0.429        | 1.18 (0.32-4.33), p=0.803              |
|                                         | <b>Education</b>                         |                                  |                                        |
|                                         | <12 years                                | -                                | -                                      |
|                                         | 12 years                                 | 1.78 (0.97-3.30), p=0.063        | 1.37 (0.70-2.68), p=0.354              |
|                                         | >12 years                                | <b>2.82 (1.46-5.43), p=0.002</b> | <b>2.09 (1.06-4.14), p=0.034</b>       |
| <b>Physical health</b>                  | <b>Physical function (SPPB) (0-12)</b>   |                                  |                                        |
|                                         | Low (0-4)                                | 1.25 (0.61-2.56), p=0.547        | 1.08 (0.50-2.32), p=0.850              |
|                                         | Intermediate- high (5-12)                | -                                | -                                      |
|                                         | <b>Low Gait speed</b>                    |                                  |                                        |
|                                         | Cannot walk                              | -                                | -                                      |
|                                         | Yes                                      | 0.87 (0.24-3.15), p=0.828        | 0.99 (0.26-3.76), p=0.987              |
|                                         | No                                       | 0.80 (0.44-1.44), p=0.448        | 0.86 (0.46-1.63), p=0.645              |
|                                         | <b>Number of chronic conditions, 0-9</b> |                                  |                                        |
|                                         | 0-2                                      | -                                | -                                      |
|                                         | 3+                                       | 1.49 (0.86-2.58), p=0.157        | <b>1.91 (1.05-3.46), p=0.033</b>       |
|                                         | <b>Diabetes</b>                          | 1.37 (0.80-2.33), p=0.249        | 1.34 (0.76-2.37), p=0.307              |
|                                         | <b>Arthritis</b>                         | 1.54 (0.88-2.67), p=0.126        | 1.44 (0.78-2.63), p=0.242              |
|                                         | <b>Stroke</b>                            | 1.43 (0.70-2.93), p=0.325        | 1.44 (0.69-3.01), p=0.333              |
|                                         | <b>Heart problems</b>                    | 1.45 (0.85-2.49), p=0.176        | <b>2.46 (1.39-4.36), p=0.002</b>       |
|                                         | <b>High blood pressure</b>               | 1.28 (0.67-2.47), p=0.451        | 2.05 (0.98-4.31), p=0.058              |

## Appendix 3.2. Continued.

|                                       |                                                  |                                    |                                    |
|---------------------------------------|--------------------------------------------------|------------------------------------|------------------------------------|
| <b>Fall history last year</b>         |                                                  |                                    |                                    |
|                                       | No fall                                          | -                                  | -                                  |
|                                       | 1 fall                                           | <b>2.12 (1.09-4.11), p=0.026</b>   | 1.37 (0.62-3.00), p=0.434          |
|                                       | 2+ falls                                         | <b>10.84 (5.53-21.26), p=0.000</b> | <b>11.98 (5.90-24.32), p=0.000</b> |
| <b>Use of mobility devise</b>         |                                                  |                                    |                                    |
|                                       |                                                  | 1.44 (0.82-2.54), p=0.202          | 1.26 (0.68-2.35), p=0.463          |
| <b>Self-perceived balance problem</b> |                                                  |                                    |                                    |
|                                       |                                                  | <b>1.80(1.06-3.06), p=0.028</b>    | <b>2.23 (1.22-4.07), p=0.010</b>   |
| <b>Pain</b>                           |                                                  |                                    |                                    |
|                                       |                                                  | 1.36 (0.80-2.29), p=0.254          | <b>1.87 (1.04-3.35) p=0.037</b>    |
| <b>Visual impairment</b>              |                                                  |                                    |                                    |
|                                       |                                                  | 1.32 (0.70-2.51), p=0.391          | 1.10 (0.56-2.19), p=0.784          |
| <b>Hearing impairment</b>             |                                                  |                                    |                                    |
|                                       |                                                  | 1.30 (0.72-2.35), p=0.389          | 1.27 (0.67-2.42), p=0.468          |
| <b>Mental health</b>                  | <b>Fear of falling</b>                           | <b>2.08 (1.24-3.49), p=0.005</b>   | <b>2.23 (1.28-3.87), p=0.004</b>   |
|                                       | <b>Probable depression</b>                       | 1.07 (0.60-1.92), p=0.822          | 1.38 (0.74-2.57), p=0.318          |
|                                       | <b>Probable anxiety</b>                          | 1.30 (0.71-2.39), p=0.400          | 1.23 (0.65-2.31), p=0.521          |
|                                       | <b>Cognitive functions (0-32)</b>                |                                    |                                    |
|                                       | Low (1 quantile,0-6)                             | -                                  | -                                  |
|                                       | Intermediate (2 quantile, 7-10)                  | <b>1.93 (1.01-3.70), p=0.048</b>   | <b>2.59 (1.32-5.09), p=0.006</b>   |
|                                       | High (3 quantile, 11-23)                         | <b>2.84 (1.50-5.37), p=0.001</b>   | 1.56 (0.77-3.19), p=0.218          |
|                                       | <b>Behavioral disturbance</b>                    | 0.98 (0.57-1.70), p=0.957          | 0.97 (0.55-1.72), p=0.928          |
| <b>Social environment</b>             | <b>Caregiving times received (hrs/week)</b>      | 1.00 (0.99-1.00), p=0.470          | 1.00 (1.00-1.01), p=0.371          |
|                                       | <b>Number of care partners</b>                   | 0.92 (0.74-1.15), p=0.458          | 0.86 (0.67-1.09), p=0.217          |
|                                       | <b>Unmet need in ADL</b>                         | 1.22 (0.54-2.75), p=0.628          | 1.94 (0.86-4.40), p=0.113          |
|                                       | <b>Unmet need in IADL</b>                        | 2.22 (0.55-8.91), p=0.261          | <b>3.90 (1.03-14.77), p=0.045</b>  |
|                                       | <b>Unmet needs in mobility</b>                   | 1.32 (0.71-2.43), p=0.379          | 1.46 (0.77-2.78), p=0.246          |
|                                       | <b>Unmet needs in any of these three domains</b> | 1.37 (0.79-2.38), p=0.268          | 1.72 (0.96-3.08), p=0.068          |
|                                       | <b>Live alone</b>                                | 0.65 (0.35-1.22), p=0.179          | <b>0.35 (0.17-0.73) p=0.002</b>    |
|                                       | <b>Informal social engagement</b>                | 0.96 (0.48-1.92), p=0.911          | 0.66 (0.32-1.37), p=0.264          |
|                                       | <b>Formal social engagement</b>                  | 1.30 (0.78-2.17), p=0.319          | 1.26 (0.72-2.19), p=0.413          |



Appendix 3.2. Continued.

|                                      |                                     |                           |                           |
|--------------------------------------|-------------------------------------|---------------------------|---------------------------|
| <b>Physical<br/>environ<br/>ment</b> | <b>Home tripping hazards</b>        | 0.66 (0.33-1.33), p=0.245 | 0.83 (0.39-1.78), p=0.636 |
|                                      | <b>Outdoor tripping<br/>hazards</b> | 0.78 (0.43-1.43), p=0.430 | 0.96 (0.50-1.84), p=0.894 |

Appendix 3.3. Variables that are associated with missing value due to institutionalization, deceased, and missing

|                                                            | Community<br>-dwelling<br>(n=362)<br>Reference<br>group | Institutionalized<br>(n=24)           | Deceased<br>(n=81)                   | Missing<br>(n=41)                    |
|------------------------------------------------------------|---------------------------------------------------------|---------------------------------------|--------------------------------------|--------------------------------------|
| <b>Age (n=508)</b>                                         | -                                                       | 1.03 (0.98-1.09),<br>p=0.277          | 0.99 (0.95-1.04),<br>p=0.713         | <b>0.92 (0.87-0.97),<br/>p=0.003</b> |
| <b>Female (n=508)</b>                                      | -                                                       | <b>4.87 (1.56-15.23),<br/>p=0.006</b> | 0.96 (0.51-1.80),<br>p=0.901         | 0.87 (0.37-2.03),<br>p=0.743         |
| <b>Race/ethnicity (n=506)</b>                              |                                                         |                                       |                                      |                                      |
| Non-Hispanic White                                         | -                                                       | -                                     | -                                    | -                                    |
| Non-Hispanic Black                                         | -                                                       | <b>0.13 (0.03-0.67),<br/>p=0.015</b>  | 0.90 (0.50-1.62),<br>p=0.730         | 1.15 (0.50-2.64),<br>p=0.747         |
| Hispanic                                                   | -                                                       | 0.63 (0.14-2.91),<br>p=0.555          | <b>0.21 (0.05-0.97),<br/>p=0.045</b> | 1.04 (0.27-4.08),<br>p=0.950         |
| Other (American Indian/Asian/Native Hawaiian/Multi-racial) | -                                                       | <b>0.00 (0.00-0.00)<br/>p=0.000</b>   | 1.59 (0.36-7.10),<br>p=0.544         | 1.50 (0.27-8.30),<br>p=0.639         |
| <b>Education (n=501)</b>                                   |                                                         |                                       |                                      |                                      |
| >12 years                                                  | -                                                       | -                                     | -                                    | -                                    |
| 12 years                                                   | -                                                       | <b>21.19 (4.19-107.1)<br/>p=0.000</b> | 1.32 (0.63-2.76),<br>p=0.458         | 0.58 (0.23-1.51),<br>p=0.267         |
| >12 years                                                  | -                                                       | <b>21.91 (4.28-112.1)<br/>p=0.000</b> | <b>2.17 (1.02-4.61),<br/>p=0.043</b> | 1.21 (0.43-3.44),<br>p=0.716         |
| <b>Number of chronic conditions, 0-9 (n=504)</b>           |                                                         |                                       |                                      |                                      |
| 0-2                                                        | -                                                       | -                                     | -                                    | -                                    |
| 3+                                                         | -                                                       | 0.71 (0.29-1.78),<br>p=0.469          | 0.84 (0.44-1.62),<br>p=0.610         | 0.90 (0.36-2.24),<br>p=0.815         |
| <b>Pain (n=506)</b>                                        | -                                                       | 1.38 (0.51-3.72),<br>p=0.530          | 0.87 (0.47-1.61),<br>p=0.654         | 2.09 (0.80-5.41),<br>p=0.130         |
| <b>Fall history last year (n=507)</b>                      |                                                         |                                       |                                      |                                      |
| No fall                                                    | -                                                       | -                                     | -                                    | -                                    |

### Appendix 3.3. Continued.

|                                                                   |   |                              |                               |                                      |
|-------------------------------------------------------------------|---|------------------------------|-------------------------------|--------------------------------------|
| 1 fall                                                            | - | 1.40 (0.44-4.45),<br>p=0.573 | 0.70 (0.29-1.67),<br>p=0.422  | 2.23 (0.80-6.27),<br>p=0.127         |
| 2+ falls                                                          | - | 1.59 (0.53-4.76),<br>p=0.405 | 1.50 (0.74-3.03),<br>p=0.263  | 1.79 (0.68-4.71),<br>p=0.241         |
| <b>Fear of falling<br/>(n=506)</b>                                | - | 0.92 (0.37-2.28),<br>p=0.863 | 0.93 (0.50-1.76),<br>p=0.834  | 0.94 (0.41-2.16),<br>p=0.884         |
| <b>Cognitive<br/>functions (0-32)<br/>(n=457)</b>                 |   |                              |                               |                                      |
| Low (1 quantile, 0-6)                                             | - | -                            | -                             | -                                    |
| Intermediate (2 quantile, 7-10)                                   | - | 1.09 (0.37-2.18),<br>p=0.872 | 0.46 (0.20-1.05),<br>p=0.066  | 0.41 (0.14-1.22),<br>p=0.107         |
| High (3 quantile, 11-23)                                          | - | 0.30 (0.07-1.28),<br>p=0.104 | 0.85 (0.39 -1.88),<br>p=0.690 | 1.53 (0.57-4.09),<br>p=0.395         |
| <b>Adverse<br/>consequences due<br/>to unmet need<br/>(n=508)</b> | - | 0.73 (0.27-1.95),<br>p=0.529 | 1.59 (0.84-3.03),<br>p=0.155  | 1.22 (0.50-2.99),<br>p=0.658         |
| <b>Live alone<br/>(n=508)</b>                                     | - | 1.57 (0.54-4.52),<br>p=0.407 | 1.11 (0.60-2.44),<br>p=0.801  | <b>0.07 (0.02-0.29),<br/>p=0.000</b> |

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EDUCATION

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- |             |               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|-------------|---------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>2021</b> | <b>PhD</b>    | <p><b>University of Washington, Seattle, WA, USA</b><br/>Social Welfare PhD program</p> <p><i>Dissertation: Developing and validating a behavioral framework of dementia caregiving in fall risk management for community-dwelling older adults living with dementia</i></p> <p><i>Qualifying paper: A mixed-method systematic review on informal caregivers' experiences of fall risk among community-dwelling older adults with dementia.</i></p> <p>Center of Statistics and the Social Sciences Certificate<br/>QUAL Concentration - Qualitative Multi-Method Research Program</p> |
| <b>2016</b> | <b>M.A.</b>   | <p><b>Xiamen University, Xiamen, Fujian, China</b><br/>Master program in Social Work Research</p> <p><i>Thesis: Practice process of social workers participating in developing health care interprofessional collaborative assessment: A participatory action research in a community-based dementia care program</i></p>                                                                                                                                                                                                                                                              |
| <b>2012</b> | <b>B.S.W.</b> | <p><b>Xiamen University, Xiamen, Fujian, China</b><br/>Bachelor of Social Work</p> <p><i>Thesis: Roles of social work in community development in urban China: A case study of a community-based care program for older adults</i></p>                                                                                                                                                                                                                                                                                                                                                 |

## FELLOWSHIPS & AWARDS

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|                     |                                                                                                                                                                                                                                                                                                                                                                                                                    |
|---------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2020 (Under review) | <p><b>National Institute on Aging (F99/K00)</b><br/>Engaging care partners in fall risk management for community-dwelling older adults living with dementia<br/>Role: Principle Investigator; \$423,524<br/>Goal: To utilize data from multiple sources to understand how to engage diverse dementia care partners in managing fall risk and translate these findings into a culturally tailored intervention.</p> |
| 2020                | <p><b>Martha H. Duggan Fellowship in Caring Labor (\$10,000)</b><br/>For graduate students committed to researching or serving those who provided caring labor.</p>                                                                                                                                                                                                                                                |
| 2019                | <p><b>National Association of Social Workers (NASW) / Council on Social Work Education (CSWE) Social Work HEALS Doctoral Fellowship (\$17,900)</b><br/>For doctoral students who demonstrated commitment to the field of health social work and engaged in dissertation research related to health care practice, policy or education.</p>                                                                         |
| 2019                | <p><b>Kath Wilham Doctoral Student Advanced Training Grant Award, University of Washington School of Social Work (\$1000)</b></p>                                                                                                                                                                                                                                                                                  |
| 2018                | <p><b>University of Washington Population Health Conference Travel Award (\$1500)</b></p>                                                                                                                                                                                                                                                                                                                          |
| 2018                | <p><b>University of Washington Retirement Association Graduate Student Fellowship in Aging (\$8109 + tuition waiver)</b><br/>Fellowship for graduate students of outstanding academic merit who have a demonstrated academic and personal interest in aging-related issues.</p>                                                                                                                                    |
| 2017                | <p><b>UW Center for Statistics and the Social Science, Graduate Student Travel Grant (\$800)</b></p>                                                                                                                                                                                                                                                                                                               |

A competitive travel grant for proposals that demonstrate sophisticated use of statistical methodology and potential for significant impact.

- 2017**                      **Outstanding Master Thesis Award in Fujian Province, China**  
A competitive annual award for outstanding master's degree thesis by graduates from universities in Fujian Province, China.
- 2016**                      **UW Graduate School Top Scholar Award (\$7662 + tuition waiver)**  
From School of Social Work funds to build competitive financial packages to attract outstanding students to University of Washington.
- 2015**                      **Favorite Social Work Documentary Prize (1st prize), awarded by University of Southern California, USC School of Social Work, Center for Asian Pacific Leadership**  
Documentary film-making team member for film that depicts the hopes and struggles of grandparents in China who traveled long distances to help care for their grandchildren. Website: <https://www.youtube.com/watch?v=Vli-CrrytGs>
- 2012**                      **Scholarship for Social Science Academy, Department of Public Affairs, Xiamen University, Xiamen, Fujian, China**  
To recognize top students who show outstanding capacities in social science research.
- 2009**                      **University Scholarship, Xiamen University Xiamen, Fujian, China**  
To recognize undergraduate students' academic and personal achievement.

## RESEARCH FOCUS & EXPERIENCES

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### Research Interests

Dementia care

Interdisciplinary collaboration

Health management for older adults living

Home- and community-based

|                                                 |                                       |
|-------------------------------------------------|---------------------------------------|
| with chronic illness and disability             | services                              |
| Informal and formal caregiving for older adults | Integrated health and social services |
| Resilience in caregiving                        | Health disparities                    |

## Research skills

|                     |                                                                                                                                                                                                                                                                                                                                                                                   |
|---------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Quantitative</b> | Causal modeling (propensity score matching), structural equation modeling, event history analysis, analysis of categorical and count data, multivariate analysis (factor analysis, item response theory, latent class analysis), longitudinal analysis, generalized linear regression analysis, handling missing data using multiple imputation (Software: R, STATA, SPSS, Mplus) |
| <b>Qualitative</b>  | Grounded theory, thematic analysis, content analysis (Software: Dedoose, Atlas.ti)                                                                                                                                                                                                                                                                                                |
| <b>Others</b>       | Participatory action research, research-practice partnership building, program evaluation, biomarker data collection, mixed methods research                                                                                                                                                                                                                                      |

## Research experiences

|                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|-----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>June. 2020 - present</b> | <b>Graduate Research Assistant</b><br>University of Washington School of Social Work<br>NIH/NIA (K01) <i>Engaging Older Adults with Cognitive Impairment in Planning for Technology Use in Their Care: The Identifying Needs for Optimal Remote Monitoring tool (INFORM)</i><br>PI: Clara Berridge, PhD, MSW<br>Responsibilities: Develop survey analysis plan; clean and analyze quantitative survey data; conduct literature review; co-author peer-review publications |
| <b>June. 2017 - present</b> | <b>Research Scientist</b><br>University of Washington School of Nursing<br>NIH/NIA (R21) <i>Promoting Caregiver Resilience During Medical Crisis of Persons Living with Dementia</i><br>PI: Tatiana Sadak, PhD, PMHNP, RN, FAAN                                                                                                                                                                                                                                           |

Responsibilities: Led the measurement development of resilience behaviors among care partners of people living with dementia; conducted a scoping review and a systematic review; generated conceptual framework for measure development; collected qualitative and quantitative data to validate the conceptual framework; developed and implemented data collection protocols; trained research staff in data collection; prepared presentations and manuscripts

- Jan. 2018 – Dec. 2018      Graduate Research Assistant**  
University of Washington School of Social Work  
*NIMH (R36) HIV Testing, Socio-political Context and Health of Latino immigrants*  
PI: Jane Lee, PhD, MSW  
Responsibilities: Conducted mixed methods systematic review; implemented quantitative (multinomial logistic regression analysis and latent class modeling) and qualitative data analysis (study conceptualization and grounded theory analysis); participated in manuscript preparation
- Sep. 2017 – Dec. 2017      Graduate Research Assistant**  
**Mar. 2020 – June. 2020**      University of Washington School of Social Work  
*Interprofessional education implementation plan for UW School of Social Work*  
PI: Taryn Lindhorst, PhD, MSW; Tessa A. Evans-Campbell, PhD, MSW  
Responsibilities: Examined literature on interprofessional social work education; facilitated interprofessional education opportunities for BASW and MSW students.
- Mar. 2017 – June. 2017      Graduate Research Assistant**  
University of Washington School of Social Work  
*Socioeconomic Status Trajectories and Later Life Physical Health*  
PI: Melissa Martinson, PhD, MSW  
Responsibilities: Conducted longitudinal analysis using Wisconsin Longitudinal Study (WLS) and supported the presentation and manuscript preparation



- Sep. 2016 – Sep. 2017**     **Volunteer researcher**  
 University of Washington Medicine, Memory Brain Wellness Center  
*Momentia in My Neighborhood (MIMN): An Asset- based Community Development Approach for Producing Dementia-Friendly Programs*  
 Practice Team: Marigrace Becker, MSW, Cayce Cheairs  
 Responsibilities: Developed program evaluation design; collected quantitative & qualitative data from participatory observation and focus group interview; analyzed the data; prepared for a conference presentation.
- June. 2015 – June. 2016**     **Graduate Research Assistant**  
 Xiamen University Department of Sociology and Social Work  
*A Participatory Action Research Project to Develop Social Workers' Role in Dementia Care Planning in Urban China*  
 Advisor: Min Tong, PhD, MSW, MA  
 Responsibilities: Synthesized literature on evidence-based practices; developed partnership between university research team and interprofessional healthcare team; developed dementia care needs assessment protocols and collaboration tools for community physicians, nurses and social workers; presentation and manuscript preparation
- June. 2015 – June. 2016**     **Graduate Research Assistant**  
 Xiamen University Department of Sociology and Social Work  
*Integrate Non-pharmacological Interventions with Social Work Practice in Community-based Dementia Care Programs in Urban China*  
 Advisor: Min Tong, PhD, MSW, MA  
 Responsibilities: Synthesized literature about non-pharmacological interventions for people with dementia; utilized participatory observation, in-depth interview, and archive data to develop a practice model of how to integrate non-pharmacological interventions with social work practice

- Mar. 2014 – Sep. 2014    Graduate Research Assistant**  
 Xiamen University Department of Sociology and Social Work  
*Developing community health promotion strategies through grandparenting in urban China*  
 Advisor: Min Tong, PhD, MSW, MA  
 Responsibilities: Reviewed and summarized literature about health promotion, intergenerational education, life education, and role of grandparenting in family health promotion to inform project design.
- Dec. 2013 – Dec. 2014    Graduate Research Assistant**  
 Xiamen University Department of Sociology and Social Work  
*Community-based Participatory Research for Utilizing Local History and Community Culture to Transform Community Governance in Urban China*  
 Advisor: Min Tong, PhD, MSW, MA  
 Responsibilities: Conducted in-depth interviews, participatory observation, focus groups, and archive data collection; qualitative data analysis; developed service protocols and policy reports for government agencies involved in planning community public services
- Mar. 2013 – Jan. 2014    Graduate Research Assistant**  
 Xiamen University Department of Sociology and Social Work  
*Developing Interprofessional Training for Community Geriatric Health and Social Care Practitioners*  
 Advisor: Min Tong, PhD, MSW, MA  
 Responsibilities: Synthesized literature about interprofessional health education; used participatory approaches in developing training modules; conducted participatory observation for implementation of trainings; evaluated programs at the organizational level.

## PUBLICATIONS

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### Peer-reviewed publications

- Zhou, Y.,** O'Hara, A., Ishado, E., Borson, S. Sadak, T. (In Press) Developing a new behavioral framework for dementia care partner resilience (CP-R): A mixed research synthesis. *The Gerontologist*. <https://doi.org/10.1093/geront/gnaa218>
- Zhou, Y.** Strayer, A. T., Phelan, E. A., Sadak, T., Hooyman, N. R. (2020). A mixed-method systematic review on informal caregivers' experiences of fall risk among community-dwelling older adults with dementia. *Health and Social Care in the Community*. 2020; 00:1-19. <https://doi.org/10.1111/hsc.13148>
- Zhou, Y.,** Ishado, E., O'Hara, A., Borson, S., & Sadak, T. (2020). Developing a Unifying Model of Resilience in Dementia Caregiving: A Scoping Review and Content Analysis. *Journal of Applied Gerontology*, <https://doi.org/10.1177/0733464820923549>
- Jen, S., **Zhou, Y.,** & Jeong, M. (2020). "You'll See": Younger Women Interviewing Older Women in Qualitative Research. *Journal of Gerontological Social Work*, 1-15. <https://doi.org/10.1080/01634372.2020.1769788>
- Lee, J. J., & **Zhou, Y.** (2020). How do Latino immigrants perceive the current sociopolitical context? Identifying opportunities to improve immigrant health in the United States. *Journal of Social Policy*, 49(1), 167-187. <https://doi.org/10.1017/S0047279419000163>
- Lee, J., Hong, J., **Zhou, Y.,** & Robles, G. (2020). The Relationships Between Loneliness, Social Support, and Resilience Among Latinx Immigrants in the United States. *Clinical Social Work Journal*, 48(1), 99-109. <https://doi.org/10.1007/s10615-019-00728-w>
- Lee, J., Yu, G., & **Zhou, Y.** (2019). Complex Patterns Across the Migration Process and Associated HIV Testing and Risk Behaviors among Latino Immigrants. *International journal of behavioral medicine*, 26(2), 175-184. <https://doi.org/10.1007/s12529-019-09768-5>
- Lee, J. J., & **Zhou, Y.** (2019). Facilitators and barriers to HIV testing among Asians in the United States: a systematic review. *AIDS care*, 31(2), 141-152. <https://doi.org/10.1080/09540121.2018.1533231>
- Wong, R., Amano, T., Lin, S. Y., **Zhou, Y.,** & Morrow-Howell, N. (2019). Strategies for

the recruitment and retention of racial/ethnic minorities in Alzheimer disease and dementia clinical research. *Current Alzheimer Research*, 16(5), 458-471.  
<https://doi.org/10.2174/1567205016666190321161901>

Under Review

**Zhou, Y.**, Johnson, I., Lee, J. J. (Revised & Resubmitted) Roles of social workers in dementia care planning: A systematic review. *Journal of Gerontological Social Work*.

In preparation

**Zhou, Y.** Developing a behavioral framework of dementia care partners' engagement in fall risk management for community-dwelling older adults living with dementia. In preparation. To be submitted to the journal *The Gerontologist*

**Zhou, Y.** Dimensions of dementia care partners' engagement in fall risk management: Exploratory factor analysis under item response theory. In preparation. To be submitted to the *Archives of Gerontology and Geriatrics*.

**Zhou, Y.** Impact of care partners' fall risk management behaviors on fall-related outcomes among community-dwelling older adults with dementia. In preparation. To be submitted to *The Journals of Gerontology: Medical Sciences*.

**Zhou, Y.** Wu, B. Racial/ethnic differences in fall risk among community-dwelling older adults living with dementia. In preparation. To be submitted to *The Gerontologist*.

**Zhou, Y.** Curse or opportunity? Impacts of falls in older adults living with dementia on their care partners. Draft completed. To be submitted to *Journal of Aging and Health*

**Zhou, Y.**, Ishado, E., Borson, S. Sadak, T. Validation of a behavioral framework for measuring resilience in dementia care partners: A Mixed-method Approach. Preparing for submission to *International psychogeriatrics*

Berridge, C., Robillard, J., **Zhou, Y.**, Kaye, J. Ethics for AI artificial companions during pandemic and normal times: Findings from an online survey. To be submitted to

the *Journal of Alzheimer's Dementia*

Berridge, C., **Zhou, Y.**, Kaye, J. Comparing preferences, comfort, and option preferences for remote monitoring technologies across age, memory loss, gender, and health history. To be submitted to *The Gerontologist*

Strayer, A., **Zhou, Y.**, Petrescu-Prahova, M., Belza, B., Berridge, C. Impact and implementation of Dementia Friends in three counties in Washington State. Draft completed. To be submitted to the *Journal of Applied Gerontology*.

Lin, S. Y., Wong, R., **Zhou, Y.**, Kang, Y., Liu, M. H., Belza, B. A scoping review of exercise adherence in dementia: influencing factors and effective strategies. Analysis completed. To be submitted to the *Journal of Aging and Physical Activity*.

## PEER-REVIEWED PRESENTATIONS

---

**Zhou, Y.** (November 2020). Developing a conceptual framework of dementia caregiving in fall risk management. Poster presentation at the Council on Social Work Education 66<sup>th</sup> Annual Program Meeting, Denver, Colorado.

**Zhou, Y.** Johnson, I., Lee, J. (November 2020). Roles of Social Workers in Dementia Care Planning: A Systematic Review. Oral Paper presentation at the Council on Social Work Education 66<sup>th</sup> Annual Program Meeting, Denver, Colorado.

**Zhou, Y.** (January 2020). Challenges and Resilience in Managing Fall Risk for Community-Dwelling Elders with Dementia: A Systematic Review on Informal Caregivers' Experience. Poster presentation at the Society for Social Work and Research (SSWR) 24<sup>th</sup> Annual Conference. Washington, DC.

Lee, J., Hong, J., **Zhou, Y.**, & Robles, G. (January 2020). Resilience Among Latino Immigrants in the United States: The Role of Social Support in Reducing Social Isolation. Oral presentation at the Society for Social Work and Research (SSWR) 24<sup>th</sup> Annual Conference. Washington, DC.

**Zhou, Y.**, O'Hara, A., Borson, S., Ishado, E., Sadak, T. (November 2019). Behavior markers of resilience in dementia informal caregivers: A thematic analysis from a

scoping review. Oral presentation at the Gerontological Society of America's 71st Annual Scientific Meeting. Austin, Texas.

Jen, S., **Zhou, Y.**, Jeong, M. (November 2019). "You'll see": Younger researchers interviewing older participants. Poster presentation at the Gerontological Society of America's 71st Annual Scientific Meeting. Austin, Texas.

**Zhou, Y.** (October 2019). Who cares: an exploratory study of informal caregivers' health promotion behaviors related to the fall risk among community-dwelling older adults with dementia. Poster presentation at the 2019 Interdisciplinary Association for Population Health Science (IAPHS). Seattle, WA.

**Zhou, Y.** (May 2019). Informal caregivers' perceptions, feelings and coping behaviors about the fall risk of community-dwelling older adults with dementia: A systematic review. Oral presentation at the Society for Prevention Research 27th Annual Meeting. San Francisco, CA.

**Zhou, Y.** (May 2019). Preventive care practice for the 'at risk' aging body/mind in the US: Informal care partners and fall risk in community-dwelling older adults with dementia. Oral presentation at the Taking Care Conference: Engaging the politics, processes, and ethics of care work. Seattle, WA.

**Zhou, Y.** (January 2019). Causal effect of caregivers' efforts in home modification on preventing falls for community-dwelling older adults with dementia. Oral presentation at the Society for Social Work and Research (SSWR) 23<sup>rd</sup> Annual Conference. San Francisco, CA.

**Zhou, Y.**, Sadak, T., Ishado, E., O'Hara, A., Borson, S. (January 2019) A scoping review of definitions and measures on resilience in informal caregivers of people living with dementia. Poster presentation at the Society for Social Work and Research (SSWR) 23<sup>rd</sup> Annual Conference. San Francisco, CA.

Lee, J., Yu, G., & **Zhou, Y.** (December 2018) Patterns of experience across the stages of migration among Latino immigrants: Understanding HIV testing and risk behaviors. Oral presentation at the 3rd Binational Conference: Mexico-United States, Monterrey Mexico.

Wong, R., Amano, T., Lin, S. Y., **Zhou, Y.**, & Morrow-Howell, N. (October 2018).

Strategies to recruit and retain African Americans in Alzheimer disease clinical research. Oral presentation at the Washington University in St. Louis Norman Seay Workshop. St. Louis, MO.

**Zhou, Y.**, Sadak, T., Ishado, E., Yip. M., Borson. S. (November 2018). Operationalizing the concept of resilience for dementia caregiving. Oral presentation at the Gerontological Society of America's 70th Annual Scientific Meeting, Boston, Massachusetts.

**Zhou, Y.** (November 2018). Effect of caregivers' efforts in home modification on preventing falls for community-dwelling people with dementia. Poster at the Gerontological Society of America's 70th Annual Scientific Meeting, Boston, Massachusetts.

Wong, R., Lin, S., & **Zhou, Y.** (November 2018). Strategies for the recruitment and retention of African Americans in Alzheimer's disease and dementia clinical research: A systematic review. Poster presentation at the American Public Health Association 2018 Annual Conference. San Diego, CA.

Ham, C., **Zhou, Y.** (July 2018). Fall preventions for individuals with dementia: An innovative partnership built in Washington State. Poster presentation at the Alzheimer's Association International Conference 2018 Annual Conference, Chicago, IL.

Martinson, M.L., **Zhou, Y.** (January 2018). Socioeconomic status trajectories and later life physical health. Poster presentation at the Society for Social Work Research (SSWR) 22<sup>nd</sup> Annual Conference, Washington, DC.

**Zhou, Y.** (June 2016). Professional foundation of social work assessment in the inter-professional healthcare practice: A participatory action research. Oral presentation at the 8th International Conference on Social Work in Health and Mental Health (ICSW2016), Singapore.

**Zhou, Y.** (November 2015). Integrating music therapy with social work practice in a home-based program of dementia care: A participatory action research in urban China. Oral presentation at the 3rd World Congress on Integrated Care (WCIC3) "Co-producing high quality people centered integrated care for ALL", Mexico City.

**Zhou, Y.** (October 2013). Exploring the logic of social work practice research: Based on the first experiment of cooperation between a university research team and a social service agency. Oral presentation at the Seminar on Social Work Practice Research in Southern China, Xiamen.

## PRACTICE EXPERIENCE

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|--------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Oct. 2016 – Sep. 2017</b>   | <b>Program Evaluation Intern</b><br>UW Medicine Memory & Brain Wellness Center, Seattle, WA<br>Conducted an evaluation of a community outreach and education program named “Momentia in My Neighborhood.”                                                                                                  |
| <b>July. 2012 – June. 2013</b> | <b>Program Social Work Intern</b><br>Community residential committee, Lvlin, Fujian, China<br>Assisted the committee to develop its youth volunteer program and elder care program, and facilitated the collaborations between social service agencies and the committee.                                  |
| <b>Oct. 2011 – July. 2012</b>  | <b>Co-Founder and Volunteer Coordinator</b><br>“Amoy Fellow” Program, Xiamen, Fujian, China<br>Led a project concerning the civic education and youth participation of the college students (over 100 volunteers), funded by “Black Apple Youth” Contest of College Student’s Social Entrepreneurship      |
| <b>Aug.2011 – Oct.2011</b>     | <b>Program Intern</b><br>Non-profit Incubator Chengdu Office, Chengdu, Sichuan, China<br>Conducted community-based, post-disaster (after May 12. 2008, Sichuan Earthquake) needs assessment for community-dwelling older adults; completed needs assessment report to local government for apply grants to |



improve community-based services for older adults in that region

**July. 2011- Aug. 2011**

**Social Work Intern**

Community residential committee, Jinjiang, Fujian, China  
Participated in community assets and needs assessment to explore program opportunities for developing intergenerational programs for youth and older adults living in a rural area in China

**Oct. 2010 – Feb. 2011**

**Social Work Intern**

Community residential committee, Xiamen, Fujian, China  
Participated in the development of a home-based care program for community-dwelling older adults, coordinated an older adults' leisure activity groups

**Sep. 2009 – Sep. 2010**

**Social Work Intern**

Guoren Migrant Workers' Home, Xiamen, Fujian, China  
Designed and implemented an educational and social services program to children whose parents were migrant workers; participated in the 3<sup>rd</sup> Art Festivals of Brave New Workers in Beijing for migrant workers advocacy

## TEACHING INTEREST & EXPERIENCE

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### Teaching interests

- Human behavior and the social environment, gerontology, disability, social sciences of health and illness, interprofessional education, migration and healthcare
- Social work history and theory, social welfare and health policy, long-term services and supports
- Research methods, mixed methods research, community-engage research

- International social work

### Teaching experience

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|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Fall 2019               | <b>Foundation of Social Welfare Research (MSW)</b>                                                                                                                                                                                                                                                                                                    |
| Fall 2020               | Sole Instructor                                                                                                                                                                                                                                                                                                                                       |
| Spring 2019             | <b>Community Service Learning (BASW)</b>                                                                                                                                                                                                                                                                                                              |
| Winter 2019             | Teaching assistant and guest lecturer:<br><i>The role of community-based participatory research in social work practice; Data collection for social change</i>                                                                                                                                                                                        |
| Winter 2019             | <b>Foundation of Social Welfare Research (MSW)</b><br>Guest lecturer: <i>Mixed methods in social work research</i>                                                                                                                                                                                                                                    |
| 2017-2018 academic year | <b>Trainee in Interprofessional Education (IPE) Teaching Fellows Program</b><br>Center for Health Sciences Interprofessional Education Research and Practice (CHSIE)<br>Completed IPE training, co-facilitated two IPE training workshops (Foundations of Interprofessional Practice) for health science students from different professional fields. |
| Winter 2018             | <b>Contexts of Disability and Anti-Ableist Practice (MSW)</b><br>Teaching practicum and guest lecturer: <i>Housing, home and community-based services.</i>                                                                                                                                                                                            |
| Fall 2017               | <b>Instructional Theory and Practice (PhD program course)</b><br>Simulation lecture on research pedagogy in social work education: <i>Goals of research course for professional education of social work (BSW/MSW).</i>                                                                                                                               |

## MENTORING EXPERIENCE

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|------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Jul. 2019 – Jan. 2020</b> | <b>Mentee: Laura Whitten, BASW Honor Program student</b><br>University of Washington, School of Social Work<br>Honor program project: The correlation between Westernized diet and poor health outcomes within the Native American population            |
| <b>Oct. 2018 - present</b>   | <b>Mentee: Avery O’Hara, Bachelor of Science in Nursing (BSN) student</b><br>University of Washington, School of Nursing<br>Mary Gates Research Scholarship project: Operationalization of resilience for care partners of patients living with dementia |
| <b>Sep.2015 – Jun.2016</b>   | <b>Mentee: Yang Qiu, MSW student</b><br>Xiamen University, Department of Sociology and Social Work<br>Research project: Inter-professional collaboration in risk assessment for people with dementia living at home: A participatory action study        |

## PROFESSIONAL MEMBERSHIPS

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|        |                                                                          |
|--------|--------------------------------------------------------------------------|
| 2018 - | Society for Social Work Research (SSWR)                                  |
| 2017 - | The Gerontological Society of America (GSA)                              |
| 2019 - | National Association of Social Workers (NASW)                            |
| 2019 - | Council on Social Work Education (CSWE)                                  |
| 2020 - | The Association for Anthropology, Gerontology and the Life Course (AAGE) |
| 2020 - | Association for Gerontology Education in Social Work (AGESW)             |

## ACADEMIC SERVICE

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|-----------|--------------------------------------------------------------------------------------------------|
| 2021      | Reviewer, <i>Journal of Applied Gerontology</i>                                                  |
| 2020      | Reviewer, <i>Health &amp; Social Care in the Community</i>                                       |
| 2020      | Reviewer, <i>Global Public Health</i>                                                            |
| 2019-2020 | Member, Faculty Recruitment Committee, UW School of Social Work                                  |
| 2018-2019 | Member, Awards Committee for Social Welfare Program for UW School of Social Work                 |
| 2017      | Abstract reviewer, International Association of Gerontology and Geriatrics (IAGG) World Congress |

## PROFESSIONAL SERVICE

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|----------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Oct. 2017 –Present</b>  | <b>Advisory Group Member</b><br>Finding Our Balance Workgroup, Washington State Department of Health, Seattle, WA<br>Workgroup for developing effective fall risk prevention interventions for high-risk and underserved older adults in Washington State                    |
| <b>Oct. 2016 – Present</b> | <b>Advisory Group Member</b><br>UW Medicine Memory & Brain Wellness Center, Community Education & Impact advisory group, Seattle, WA                                                                                                                                         |
| <b>July. 2020</b>          | <b>Invited Presenter</b><br>Virtual Community Wellness Talk, organized by UW Medicine Memory & Brain Wellness Center<br>Gave a presentation to people living with memory loss and care partners, titled “Preventing falls in people with dementia: What can we do together?” |

**June. 2018**

**Volunteer Exercise Coach**

UW Medicine Memory & Brain Wellness Center, Seattle,  
WA

Volunteered as an exercise coach for a 2-week wellness  
program for people with early memory loss and their care  
partners

## LANGUAGES

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Mandarin (native), English (fluent)