Person-Centered Care of Older Adults with Cognitive Impairment and Their Care

Partners: Cultural Relevance and Dyadic Experience in China

by

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Dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing in the Graduate School of Duke University

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Abstract

**Problem:** Dementia has become a global public health priority. A total of 47 million people worldwide lives with dementia, and nearly 60% of whom live in low- and middle-income countries (LMIC). The fastest growth of population living with dementia takes place in China. In addition, the number will be greater if we take persons with mild cognitive impairment (MCI) into account. The estimated prevalence of MCI and dementia among older adults in China is between 13% and 20%. My population of study are persons with cognitive impairment (PWCI) and their family care partners, including those living with MCI or mild dementia. It is estimated that over 80% of the population with cognitive impairment in China are living in the community and receiving care from their informal caregivers.

There is a severe lack of residential dementia care service and dementia management support at community level in China. The lack of supportive resources and quality services in China posed severe challenges to PWCI and their family care partners. The complexity of PWCI and their care partners’ changing experience of living with cognitive impairment is interpreted in the dynamic nature of their spousal relationship and relationship with others, patterns of communication, daily activities and care during the extended period of cognitive decline. The purpose of my dissertation is to describe the cultural relevance of person-centered dementia care in
home and community-based setting and provide empirical evidence for understanding the changing experience of living with cognitive impairment through the dyadic experiences of PWCI and their spousal care partners.

**Methods:** We used semi-structured open-ended interviews (Ashton, 2014) to explore the experiences and perceptions of PWCI and their care partner’s, regarding living with cognitive impairment, working with each other, communicating with each other and taking care of each other. We then applied the person-centered dementia care framework, and Nolan’s senses framework to the analysis of the interviews to understand their experiences and perceptions. We conducted a longitudinal qualitative study of a subset of 6 dyads of PWCI and their care partners over three years with three data collection time points (2015 to 2017). We employed the approach of prospective QLS in this study to capture the complexities of relationships, experiences, and the impact on health policy.

**Findings:** Person-centered care processes are a means of establishing and nurturing the healthy relationships between PWCI and their care partners. Our findings suggest that PWCI and their spouses experience the six senses through the person-centeredness in their daily interactions with each other. It also indicated successes and challenges to being person-centered early in the disease and identified their unmet needs as well as barriers and facilitators to improve their well-being. PWCI and their care partners used strategies to adapt to the changes and cope with challenges. The
dyads experienced a lack of sense of continuity of their relationships, communication patterns, and daily life and activities. PWCI and their care partners have a lack of access to clinical expertise and quality care services in the home and community-based settings and formal LTC settings. It is acknowledged that PWCI deserves opportunities to be engaged in meaningful social relationships with others. It is crucial to help PWCI and their care partners choose a more positive attitude and nurturing the belief that there is a significant meaning in the journey of living with cognitive impairment. A lack of knowledge of the disease, treatment, and caregiving can potentially negatively affect PWCI and their care partners’ coping and overall well-being throughout the process of living with cognitive impairment. Our findings also provided many examples of when care partners respected PWCI’s choices, regarding caregiving as assisting and guiding PWCI to help themselves instead of telling them what to do, resulting in a profound positive impact on the well-being of PWCI and their care partners and most importantly, on their spousal relationships.
Dedication

This dissertation is dedicated to my loving family, my late father, my dissertation committee, friends, and to all the persons with cognitive impairment and their care partners on their journeys to embrace love and hope.
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1. Introduction

1.1 Problems and Significance

1.1.1 Prevalence and Trend of Dementia

Dementia is a syndrome defined by the decline or loss of memory and other cognitive and functional abilities, including difficulties with thinking, language, reasoning and behavioral abilities that affect a person’s daily life and activities (Gale, Acar, & Daffner, 2018). It ranges in different stages from the mildest stage when it begins to interfere with a person’s daily life to the most severe stage when the person is dependent on others for basic activities of daily living (ADL). It can be caused by a wide array of diseases and conditions. The most common ones are Alzheimer’s Disease (60-70%), vascular disease, Lewy body disease, and frontotemporal degeneration (Winblad et al., 2016). Dementia has become a global public health priority (World Health Organization and Alzheimer’s Disease International, 2012). A total of 47 million people worldwide lives with dementia, and nearly 60% of whom live in low-and middle-income countries (LMIC) (Prince, Comas-Herrera, Knapp, Guerchet & Karagiannidou, 2016). The number is projected to increase to 152 million in 2050. The fastest growth in this population is taking place in China (Wimo et al., 2017). The population with dementia in China reached 8.18 million, with 360,000 new cases being diagnosed each year (N. Li et al., 2015).
In addition, the number will be greater if we take persons with mild cognitive impairment (MCI) into account. MCI is an intermediate state between normal cognitive aging (becoming increasingly forgetful) and dementia. Although not all MCI converts to dementia, it is strongly associated with an increased risk of dementia (Petersen et al., 2014; Vega & Newhouse, 2014). Those with MCI and early-stage dementia can have an extended period of time of cognitive decline. Even though it is extremely challenging to provide care for those with advanced dementia, studies indicate that supporting persons with MCI and mild dementia can be difficult during the extended time period of cognitive decline because of the uncertainty and constantly changing needs and daily routines (Spingate & Tremont, 2013). Therefore, it is crucial to explore and understand their experiences in the extended process of transitioning from MCI to mild dementia. The estimated prevalence of MCI and dementia among older adults in China is between 13% and 20% (Nie et al., 2011; Ding et al., 2015). My population of study are persons with cognitive impairment (PWCI) and their family care partners, including those living with MCI or mild dementia.

Person-centered care is the preferred way to approach dementia care and has become, in Western countries, the standard of care (Edvardsson et al., 2010). Evidence shows that person-centered care may reduce PWCI’s dementia-related behavioral symptoms (Edvardsson, Winblad, & Sandman, 2008). Thus, creating foundation for
person-centeredness early in the disease is important. However, the majority of studies neglect PWCI by exclusively focusing on family caregivers or only indirectly including PWCI’s characteristics (Cheng, 2017; Rolan & Chappell, 2015). Very few studies embrace dyadic variables or perceptions to understand how the change in cognitive function affects their life and their relationship from both sides (Bosco et al., 2018; Wawrziczny et al., 2016).

1.1.2 Care Arrangement of Persons with Cognitive Impairment in China

Many diseases and conditions that lead to dementia are progressive, thus, a person’s dementia-related symptoms and care needs are likely to change over time (Winblad et al., 2016). With the progression of cognitive impairment and decline in functional abilities, PWCI require increased care in formal long-term care (LTC) settings and/or home and community-based settings (Wang, Xiao, He, Ullah, & De Bellis, 2014). However, residential dementia care services are not readily available in China (Chen, Boyle, Conwell, Xiao, & Chiu, 2014). In certain circumstances, persons diagnosed with dementia are excluded from some forms of health care, such as inpatient care or residential care in China because of unprepared workforce and limited space in these facilities (Wang et al., 2019). The cultural expectations of aging in place also affect their choices (Wang et al., 2014). Therefore, it is estimated that over 80% of the population
with cognitive impairment in China are living in the community and receiving care from their informal caregivers (Wang, Xiao, & Li, 2018).

1.1.3 Community-Dwelling Persons with Cognitive Impairment and Their Family Care Partners

PWCI in the early stage are often capable of understanding their diagnosis and making decisions (Smith & Buckwalter, 2005). Even though, their cognitive function declines over time, PWCI are able to remain active in social and community activities (Snyder, Caprio, Wessell, Lin, & Hanson, 2013). Family care partners are key persons to provide care and promote health management for PWCI (Prince et al., 2013). Ideally, PWCI and their family care partners maintain a partnership in daily activities, care and health management (McCormack & McCane, 2006; Nolan et al., 2004). However, PWCI’s needs and preferences are often overlooked in the process of decision making and daily activity planning even though they are receiving care from their families at their own homes (Steeman, De Casterle, Godderis, & Grypdonck, 2006).

PWCI may become increasingly withdrawn due to their progressive decline of ability to complete activities of daily living. Reduced tolerance of stress and resistance to care are also seen among PWCI (Wu, Yue, & Mao, 2015). The lack of access to quality care services poses great challenges to PWCI and their family care partners (Prince et al., 2016). It is equally important for PWCI to be the center of their care planning and
delivery compared to those without cognitive challenges. However, when engaging in care for persons with dementia, care partners are so overwhelmed by the increasing caregiving burden that they tend to focus on the disease, symptoms, and behavior management while losing sight of the person with cognitive impairment (Durgahee & Durgahee, 2012; Fazio, Pace, Flinner, & Kallmyer, 2018).

It can be stressful and painful for PWCI’s family care partners to manage their cognition-related psychological and behavioral symptoms and declined physical functions, watch their loved one’s characteristics changing over time or see them in distress (Chan et al., 2010; Hong & Coogle, 2016). They try to make sense of the situation and find meaning of providing care for PWCI (La Fontaine & Oyebode, 2014). However, there is a severe lack of residential dementia care service (Chen et al., 2014; Wang et al., 2016) and dementia management support at community level in China (Wang et al., 2014; Wittenberg & Hu, 2016). The lack of supportive resources and quality services in China posed severe challenges to PWCI and their family care partners.

The number of older adults living in empty nest families reached 50 million due to changed family structures and increasing numbers of adult children moving away from their family for employment (Peng & Wu, 2015). Thus, a huge number of PWCI receive primary care from their spouses. However, some spousal care partners have age-related conditions or chronic illness burden, widening the gap between caregiving
capacity and care needs from PWCI (Dai et al., 2013; Bruan et al., 2009). PWCI and their spousal care partners have established patterns of interaction and communication in their spousal relationship, such as their way of expressing themselves, reacting to each other, and expectations of each other (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013). PWCI and their care partners tend to experience continuous changes and adjustments to their spousal relationship when they are living with cognitive impairment (Arbel, Bingham, & Dawson, 2019). For example, deterioration and challenges in communication are perceived as associated with lowered relationship quality by spousal care partners (Braun et al., 2009). Like other family care partners, they try to make sense of the situation and interpret impact on their spousal relationships. Evidence shows that the spousal care partners of PWCI are vulnerable to chronic stress, depression, and other negative affections (Ducharme et al., 2013). PWCI’s awareness of their situation and concerns about becoming a burden to their family maintains and do not diminish in the mild stage of dementia (Steeman et al., 2006). Ideally, PWCI and their care partners’ establish an interdependent and reciprocal relationship with one another and they collaborate with each other to build shared goals and adapt to changes in their daily life and care. It is crucial to simultaneously explore what is happening with PWCI and their spousal care partners over time in the context of their relationship.
1.1.4 Person-centered Care and Person-centered Dementia Care

PWCI can experience a feeling of loss and grief, particularly the sense of autonomy. Evidence shows that care partners can play significant roles in helping PWCI to maintain their sense of autonomy (Ryan, Nolan, Reid, & Enderby, 2008). PWCI have the need to continue to be themselves and maintain the normality of their life as much as possible at all stages of dementia (Edvardsson, Fetherstonhaugh, & Nay, 2010). Tom Kitwood first pointed out in his foundational work of person-centered dementia care that cognitive impairment is only one aspect of the person’s current being (Kitwood & Bredin, 1992). The past two decades witnessed significant theoretical progress in person-centered care (PCC), such as the ‘Senses Framework’ (Nolan et al., 2004), advancement of the core concepts of person-centered dementia care (Edvardsson & Innes, 2010), and PCC framework from nursing perspective (McCormack & McCance, 2006; McCormack & McCance, 2011). Person-centered dementia care acknowledges persons with dementia as competent persons who deserve full respect and right to establish and maintain their social relations and make decisions for themselves (Edvardsson et al., 2010; Kitwood, 1993). Their personhood is concealed rather than lost through the progression of their disease (Mitchell & Agnelli, 2015).

Person-centered care does not simply require care providers to do whatever a care recipient wants. The concept of person-centered care is complex and multi-
dimensional, depending on the setting in which care is provided (Brownie & Nancarrow, 2013). It is based on a collaborative decision-making process that incorporates a person’s value, cultural beliefs, self-identity, and preferences with care providers’ expertise, in accordance with the principles of evidence-based practice (Edvardsson et al., 2010; Fazio et al., 2018). The core aspects of person-centered care are to prioritize the person’ well-being and needs over the completion of routine work and tasks and build care around the needs of the person (Kogan, Wilber, & Mosqueda, 2016). Although needs and preferences vary according to one’s personality and conditions, they are to be recognized, valued, translated, and addressed actively in the provision of care (Fazio et al., 2018). Crandall et al. (2007) noted that “elements of person-centered care include personhood, knowing the person, maximizing choice and autonomy, comfort, nurturing relationships, and a supportive physical and organizational environment” (p. 48).

The health care model for persons with dementia is medically-dominated and task-focused (Wang et al., 2019). Health care professionals and nursing aides tend to prioritize the completion of their routines and tasks rather than the personalized needs of PWCI and their family (Wang et al., 2016). In contrast, increased advocacy of and commitment to person-centered dementia care has been valued in western Europe and North America (Love & Pinkowitz, 2013; Fazio et al., 2018; Winblad et al., 2016). Person-
centered care was listed as a fundamental goal of quality dementia care by the Dementia Care Practice Recommendations. Person-centered care is the underlying philosophy of the 2018 Alzheimer’s Association Dementia care practice recommendation (Fazio et al., 2018). Person-centered dementia care guided interventions is evidenced to decrease agitated behaviors and physical restraints among PWCI and was also evidenced to produced more positive affections and decrease perceived caregiving burden among their caregivers (Edvardsson, 2010; Brownie et al., 2013). It is an approach to dementia care that can enhance quality of life or care for PWCI and their care partners (Fazio et al., 2018; Li et al., 2014; Whitlatch et al., 2018).

However, how can spousal family care partners provide person-centered dementia care for community-dwelling PWCI is understudied. In the context of care in one’s home, people may tend to assume that the care provided by one’s family is easily person-centered. However, the biological nature of the progression of dementia means that PWCI and their care partners must adjust to continuous changes and challenges (Vega et al., 2014). Considering the importance of the context of relationship within the family, Nolan et al. (2004) suggests that we transfer the focus of person-centered care from exclusively on individuals to a more relationship-centered focus on all persons involved in PWCI’s daily life and activities. Evidence indicates that caregivers are less likely to experience stress when they focus less on care tasks and symptoms but more on
family dynamics and relationships (Edvardsson, Winblad, & Sandman, 2008). By exploring how PCC is or is not achieved in the context of PWCI and their care partners, we can identify critical levers to support enhance quality of care and their quality of life.

1.1.5 Cultural Context

It is imperative to understand person-centered care under the unique socio-economic and cultural context of care in China. PWCI and their spousal care partners should be viewed as a unit of care within communities where they reside under a certain socio-economic and cultural context of care.

The pension and insurance system and limited savings of the current generation of older adults posed financial challenges to cover their healthcare expenses and long-term care after retirement (Wang, Béland, & Zhang, 2014). Psychogeriatric services in China are expanding, but fall far short of the demand (Xu, Hsiao, Denq, & Chi, 2017). At present, the availability of inpatient services and trained personnel is very limited. Psychological support for care partners of people with dementia is very limited and is not easily accessible to them. In fact, most PWCI will visit neurologists in China if they want to seek access to cognitive impairment-specific expertise (Shubhakaran, Wang, Khichar, Liu, & Tan, 2014). It is estimated that up to 70% of them are under the care of neurologists, which may be seen as a reflection of overmedicalization because, in general, their behavioral and psychological dysfunctions may be more effectively
managed by other professions, such as psychologists, social workers, and nurses in a person-centered manner (Xu et al., 2017).

The social and cultural construction of dementia in China also affects their perceptions and experience. The Chinese terminology of dementia “lao nian chi dai” is described with negative connotations, in which, “lao nian” means the elderly, “chi” means confused or stupid, and “dai” means losing one’s mind or being catatonic. The Chinese terminology of cognitive impairment carries negative meanings (Dai et al., 2013). The use of these terms increases stigma associated with cognitive impairment, which contributed to the delay of their seeking for professional or other external help (Dai et al., 2015). Conversely, in some Chinese communities, they hold a traditional belief that older adults are returning to a childish state. Therefore, the major cognitive impairment symptoms become normalized and viewed as part of the normal aging process, particularly among persons with aMCI and early-stage dementia (Hsiao, Liu, Xu, Huang, & Chi, 2016). This belief decreases their literacy of cognitive impairment, which in turn may also impact their help-seeking and medical adherence.

Confucianism recognizes treating others with respect as a core concept in moral practice, which is consistent with the core concept of person-centered care (Nolan et al., 2004). However, some of the ethos in traditional Chinese culture can be barriers to the implementation of PCC. For example, the concept of patient-hood: Patients are
regarded as weak and vulnerable persons who always need to be protected and cared for by their families (Kong, Fang, & Lou., 2017). In contrast to the person in PCC, PWCI are seen as patients in Chinese culture who should be taken care of by their informal caregivers (Dai et al., 2013; Liu, Insel, Reed, & Crist, 2012). This concept of patient-hood rather than personhood is a potential cultural barrier to recognizing PWCI as competent persons who deserve the right to engage in social networks and activities and making decisions or shared decisions at home. Chinese care partners tend to avoid direct conflicts and disclosures of challenges and difficulties within the family to maintain relational harmony (Au, Shardlow, Teng, Tsien, & Chan, 2012). It will be essential to have in-depth understand of home and community-based care and the degree to which person-centered care occurs or could occur, which requires careful application of the cultural context of dementia care in China.

1.2 Conceptual Model

The focus of the overall study is to explore and understand the changing dyadic experience of persons with cognitive impairment and their care partners from a person-centered care lens in the social and cultural context of China. PWCI and their care partners build and sustain an interdependent relationship within a coordinated community in which they feel being loved and empowered to experience well-being and engage in meaningful activities (Brownie et al., 2013). PWCI face challenges in social
networks as their deterioration in cognitive function affects their ability to interact with others as much as before (Schaber, Blair, Jost, Schaffer, & Thurner, 2016). Their primary care partners also experience changes in their social networks because of the increasing caregiving burden and other sociocultural factors (Cheng, 2017). The conceptual model of person-centered dementia care in home and community-based setting (See Figure 1) can help us capture the subtle changes in their relationships and experiences and understand factors that might affect the changes.
The thriving of PWCI and his or her care partner is supported by the person-centered process within a coordinated community and under the influence of sociocultural factors. PWCI and his or her care partner experience dynamics of their relationships and changes in their social networks. The outcomes are achieved in person-centered process, such as adaptable and effective communication, shared understanding of the current situation, sympathetic presence, empowerment, and prioritizing PWCI’s well-being over completion of scheduled work (Kong et al., 2017; Edvardsson et al., 2010; Fazio et al., 2018). The process is impacted by the acceptance and interpretation of person-centered care within each family unit and community, where all persons involved should be able to openly communicate with one another (Zhong & Lou, 2012; Kong et al., 2017). Operationalization of PCC is incomplete without taking traditional culture into account. Some of the cultural factors can serve as a prerequisite or facilitator for implementation of PCC. However, some notions can interfere with PCC, such as patient-hood, seeking for family harmony by avoiding different voices, direct conflict and open communication (Kong et al., 2017).

The model can guide us into exploring potential barriers and facilitators in promoting person-centered care, similarities and disparities in dyads’ perceptions and
interpretation of their experience within a socio-cultural context, and the changes of their experiences and relationships over time. The model will further help us to reflect on their dyadic or family-based interactions to identify their unmet needs, gaps and possibilities of facilitating person-centeredness in their daily experience.

Taking care of PWCI at home affects the interactional patterns and role functioning of various family members in the household and those of the extended family (Dai et al., 2013; Liu & Wang, 2013). In fact, person-centered care is not an individualized concept. It values the importance of the context in which the person exists (Edvardsson et al., 2010; Kogan et al., 2016). The model guides us to view community-dwelling PWCI and their family care partners as a unit of care in the sociocultural context. An exploration of how personhood is preserved and suggested in the context of the dyadic experience will be a critical exploratory step to develop culturally-sensitive person-centered dementia care model to optimize quality of life of PWCI and their care partners in China.

1.3 **Purpose Statement and Aims**

Experiences of PWCI and that of their primary family care partners are changing in the sense of their progressive conditions, changing perceptions of their personhood, and the dynamic nature of their relationships (Fazio et al., 2018). The purpose of my dissertation is to understand PWCI and their spousal care partners’ changing dyadic
experiences of living with cognitive impairment. My dissertation explored the dyads’ perceptions and interpretation of the changes in their experiences and relationship over time within a socio-cultural context. I focused on dyadic interactions to identify their unmet needs, gaps and possibilities of facilitating person-centeredness in their daily life.

1.3.1 Chapter 1 Aim

Introduce the problem and significance of the study.

1.3.2 Chapter 2 Aim

Provide an overview of the socio-cultural context of implementing person-centered dementia care in China and understand person-centered dementia care model with connection to senses framework.

1.3.3 Chapter 3 Aim

Explore and understand the dyadic experience of PWCI and his or her care partner through a person-centered care lens in the social and cultural context of China.

1.3.4 Chapter 4 Aim

Explore and understand the changing dyadic experience and relationships of PWCI and his or her care partner through their navigation of living with cognitive impairment over time.
1.3.5 Chapter 5 Aim

Synthesize the findings in Chapter 2-4 to understand the cultural relevance of person-centered care within the experience of PWCI and his or her care partner over time in the home and community-based settings in China.
2. Person-centered Dementia Care in China: A Bilingual Literature Review

2.1 Introduction

In 2018, over 50 million people worldwide were living with dementia, nearly 60% in developing countries, with the fastest growth taking place in China (Prince et al., 2013; Winblad et al., 2016; Wimo et al., 2017). The current number of older adults diagnosed with dementia in China reached 8.18 million in 2015; on average over 360,000 new cases are diagnosed every year (Li et al., 2015). Overall, there is a shortage of quality workforce at all levels and a lack of variety of services and programs provided in China’s long-term care (LTC) system (Song, Anderson, Corazzini, & Wu, 2014). In contrast to the substantial increase in the overall population with dementia in China, there is very limited availability of residential care services and a severe lack of community-based services for persons with dementia and their informal caregivers (Wang, Xiao, & Li, 2018; Hsiao, Liu, Xu, Huang, & Chi, 2016). Many LTC facilities do not admit persons with dementia, mainly due to lack of trained staff and limited space in these facilities (Wang, Wang, Cao, Jia, & Wu, 2018; Wu, Mao, & Zhong, 2009). Also, there is a strong cultural preference for aging in place among older adults and their family members (Sereny, 2011). Thus, informal caregivers (i.e. their family members, relatives, friends, and other unpaid caregivers) play a major role in caring for persons with dementia in China (Wang, Xiao, He, & De Bellis, 2014). This contrasts sharply with
care approaches in community and LTC settings. In big cities of China, older adults with
cognitive impairment can go to memory clinics in tertiary hospitals for diagnosis,
cognitive assessment, and prescriptions. Some older adults with dementia reside in LTC
facilities or community hospitals despite the limited availability of dementia-specific
programs. The ethos of caring for persons with dementia in health care systems is
medically-dominated, disease-oriented and task-focused (Xu, Hsiao, Deng, & Chi, 2018).
Care providers tend to prioritize routines and tasks ahead of the individualized
preferences of persons with dementia (Wang et al., 2016). In contrast, in western Europe
and North America, the past decade has seen a significantly increased commitment to
person-centered care that is relationship-focused, collaborative, and holistic for persons
with dementia, where the focus is on quality of life as perceived by care
recipients/patients, and staff and care recipients share a feeling of community and
belonging (Love & Pinkowitz, 2013; Fazio, Pac, Flinner, & Kallnyer, 2018; Winblad et al.,
2016).

Generally known as the founder of the concept of person-centered dementia care,
Tom Kitwood’s influential work emphasized the importance of giving voice to and
supporting personhood of persons with dementia by establishing systems of care that
facilitate deep and mutually empathic relationships between people (Kitwood & Bredin,
1992). Kitwood’s work recognizes that the personhood of persons with dementia is
neither diminished nor lost, but rather is concealed, as those relationships become impaired over the progression of the disease (Kitwood, 1993). Since then, there has been significant conceptual and theoretical advancement in person-centered care (PCC), such as the ‘Senses Framework’ (Nolan et al., 2004), conceptualization of core concepts of person-centered dementia care (Edvardsson & Innes, 2010), and the person-centered nursing framework (McCormack & McCance, 2006; McCormack & McCance, 2011). The most consistently-applied and fundamental philosophical prerequisites of person-centered dementia care in the literature are that all persons with dementia are recognized as valuable and competent, as having dignity, autonomy, and worth, and deserving of full respect (Edvardsson et al., 2010; Kitwood, 1993). Core principles of person-centered dementia care include knowing and valuing the person with dementia, interpreting behaviors from the person’s viewpoint, promoting a continuation of self and normality, providing a positive social environment in which they can live well, with opportunities to establish relationships that have therapeutic benefits and nurture relationships in the wider community (Love et al., 2013; McCormack & McCance, 2006). This has profound implications for how care is provided to people with dementia. Person-centered dementia care is responsive to the preference of the person with dementia and contingent upon knowing the person through an interpersonal relationship. Shifting the focus of person-centered care from individual needs to a
relationship-centered focus on interactions among all persons involved in caring relationships is also recommended (Nolan et al., 2004). Strategies for delivery of person-centered care include weaving information about the person into every interaction and activity, providing validation therapy, prioritizing the person’s well-being ahead of routines and care tasks, staying in the present, and looking for opportunities for meaningful engagement beyond scheduled activities (Edvardsson et al., 2010). Although little empirically rigorous research has tested the effects of person-centered dementia care, person-centered dementia care has been shown to promote caregivers’ sense of achievement and improve caregiver relationships with care recipients by guiding caregivers to increase focus on interactions with care recipients (Edvardsson, 2015). The literature also indicates that caregivers are less likely to experience role strain with a focus on relationship than with a focus on care tasks, specific conditions and symptoms (Edvardsson et al., 2008).

Currently available studies have been predominantly focused on populations in Western European and North American countries. Although PCC has become a priority in dementia care in these countries (Bartlett & O’Connor, 2007; Chenoweth et al., 2009; Penrod et al., 2007), it is still a relatively new concept in China. While the core principles of person-centered dementia care may be globally-relevant and not culturally-specific, however, how to implement person-centered dementia care in daily practice is
influenced by social and cultural contexts. Medically-dominated and task-oriented care models interfere with the awareness and appreciation of person-centered dementia care. Furthermore, even though some caregivers might innovate their own person-centered approaches based on their knowledge of the person with dementia, such strategies can be unsustainable if not fully supported and appreciated. Thus, with the growing population of people with dementia in China, and the need to improve quality of care for persons with dementia in LTC and community care settings, it is important to explore the concept of person-centered dementia care in China. Therefore, we conducted a literature review to understand the relevance and appreciation for person-centered dementia care in China and to identify any cultural concepts that might impact uptake of person-centered dementia care in China.

2.2 Approach

Our team is transnational and bilingual and emerged from the WE-THRIVE collaborative, which engaged LTC researchers in China, US, and numerous other countries in collaborative international LTC research (Corazzini et al., 2019). We conducted a bilingual, English and Chinese, literature review on person-centered dementia care in China. Our initial literature search had scant results, so we broadened the search terms to include literature on PCC in China. We collected, screened, and
analyzed literature in English and Chinese, as described below and depicted in the flow chart (See Figure 2).
Figure 2. Flow Chart
In English, we searched PubMed, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), and SCOPUS. We used indexed vocabulary and keywords—including “person-centered(centred) care”, “person-centeredness (centredness)”, “personhood”, “individualized (individualised) care”, “senses framework”, “relationship-centred care”, “empowerment”, and “shared decision making”—and found eighty-two articles with our search terms in their titles or abstracts. After removing duplicates, thirty-eight articles remained. We reviewed the titles and abstracts and excluded articles that did not address person-centered dementia care, PCC or core concepts of PCC of older adults and that did not occur in China. Two additional articles were culled from article reference lists. At the end of this search process, we retained ten English articles, with five conducted in Mainland China and five in Hong Kong and Taiwan.

We also searched two Chinese databases, i.e. China National Knowledge Infrastructure (CNKI) and Wanfang, using Chinese keywords related to PCC. After removing duplicates, fifty-three articles were retrieved, among which, most articles used PCC as a not clearly-defined concept in health care that is consistent with the Chinese socialist concepts “harmonious society” and “human-oriented outlook on development”. The full text of the remaining eight articles were then reviewed. Two articles reviewed person-centered therapeutic interventions among persons with
dementia in western countries (excluded); Two articles talked about benefits of PCC based on studies and experience in western countries (excluded). Finally, four articles were retained. Therefore, we included nine English and four Chinese articles.

We extracted information from each article into a matrix (Garrard, 2013) summarizing basic information and key findings (See Table 1). We read through the articles to extract content related to how person-centered care is defined, operationalized, measured, and discussed to identify themes among articles, and we analyzed and synthesized the findings by themes in the current literature review. We drew upon the PCC conceptual frameworks and models in Western Europe and North America, including the person-centered nursing framework (McCormack et al., 2006) and Senses framework (Nolan et al., 2004) to outline a conceptual framework of person-centered dementia care in China. We used the synthesized findings from the included articles to further develop and describe the person-centered dementia care model (See figure 3).
<table>
<thead>
<tr>
<th>Year</th>
<th>Author</th>
<th>Research country</th>
<th>Title</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996</td>
<td>F-J. Shih</td>
<td>China</td>
<td>Concepts related to Chinese patients’ perceptions of health, illness, and person: issues of conceptual clarity</td>
<td>The philosophies related to the concept of personhood not only influence Chinese patients’ values and beliefs, but also determine their perceptions of health, illness and nursing care.</td>
</tr>
<tr>
<td>2007</td>
<td>Julia Tao, Lai Po Wah</td>
<td>Hong Kong, China</td>
<td>Dignity in long-term care for older persons: a Confucian perspective</td>
<td>The insights of the Mencian theory of human dignity are used to provide a moral foundation for long-term care for elder persons in a context of diminishing personhood and shrinking autonomy.</td>
</tr>
<tr>
<td>2017</td>
<td>Sui-Ting Kong, Christine Meng-Sang Fang, and Vivian W. Q. Lou</td>
<td>Hong Kong, China</td>
<td>Solving the “Personhood Jigsaw Puzzle” in Residential Care Homes for the Elderly in the Hong Kong Chinese Context</td>
<td>Narratives from medical and social care practitioners in care homes demonstrated their understanding of the practice processes: “understanding the person-in-relationship and person-in-time,” “identifying the personhood-inhibiting experiences,” and “enabling personalized care for enhanced psychosocial outcomes.”</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Location</td>
<td>Study Details</td>
<td>Methodology</td>
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<tr>
<td>2010</td>
<td>NL Chappell, KL Chou</td>
<td>Hong Kong, China</td>
<td>Chinese version of staff-based measures of individualized care for institutionalized persons with dementia.</td>
<td>Empirical</td>
</tr>
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<td>2013</td>
<td>Xuebing Zhong, Vivian Lou</td>
<td>Xi’an, China (Mainland)</td>
<td>Person-centered care in Chinese residential care facilities: a preliminary measure</td>
<td>Empirical</td>
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<td>2016</td>
<td>Mao, P., Xiao, D., Zhang, M., Xie, F., Feng, H.</td>
<td>Hunan, China</td>
<td>Hunan Sheng Yanglao Jigou Chidai Zhaohu Danyuan Yirenweizhongxin de Zhaohu Xianzhuang Fenxi [Person-centered dementia care in eldercare institutions in Hunan Province]</td>
<td>Empirical</td>
</tr>
<tr>
<td>2017</td>
<td>Le Cai, Gerd Ahlström, Pingfen Tang, Ke Ma, David Edvardsson, Lina Behm, Haiyan Fu, Jie Zhang, Jiqun Yang</td>
<td>Kunming, China (Mainland)</td>
<td>Psychometric evaluation of the Chinese version of the Person-centered Climate Questionnaire - Staff version (PCQ-S)</td>
<td>Empirical</td>
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<td>Year</td>
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<tr>
<td>2018</td>
<td>Yang, Yun., Xiao, D., Mao, P., Xia, M., Zhang, W., Feng, H.</td>
<td>China (mainland)</td>
<td>Yirenweizhongxin de Yanglaojigou Zhaohuhuanjing Wenjuan [Research on reliability and validity of Person-centered climate questionnaire-staff version in pension institution]</td>
<td>Empirical Chinese Nursing Research (Chinese)</td>
</tr>
<tr>
<td>2018</td>
<td>Yao Wang, Lily Dongxia Xiao, Yang Luo, Shui-Yuan Xiao, Craig Whitehead and Owen Davies</td>
<td>Shanghai, China (mainland)</td>
<td>Community health professionals’ dementia knowledge, attitudes and care approach: a cross-sectional survey in Changsha, China</td>
<td>Empirical BMC Geriatrics</td>
</tr>
<tr>
<td>2018</td>
<td>Jing Wang, Junqiao Wang, Yuling Cao, Shoumei Jia, &amp; Bei Wu</td>
<td>Shanghai, China (Mainland)</td>
<td>Perceived Empowerment, Social Support, and Quality of Life Among Chinese Older Residents in Long-</td>
<td>Empirical Journal of Aging and Health</td>
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<tr>
<td>Year</td>
<td>Authors</td>
<td>Location (Mainland)</td>
<td>Title</td>
<td>Methodology</td>
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<td>2017</td>
<td>Yao Wang, Lily Dongxia Xiao, Shahid Ullah, Guo-Ping He, Anita De Bells</td>
<td>Changsha, China</td>
<td>Evaluation of a nurse-led dementia education and knowledge translation program in primary care: a cluster randomized controlled trial</td>
<td>Empirical</td>
</tr>
<tr>
<td>2017</td>
<td>Zhao, X.</td>
<td>China</td>
<td>Weirao Yi Laorenweizhongxin zhaohu Linian Jinxing Sheji [Older adults-centered care design].</td>
<td>Review</td>
</tr>
</tbody>
</table>
Figure 3. Model of Person-centered Dementia Care in China
2.3 Findings

We learned from the four Chinese language articles that PCC is a new concept in China; organizational support for PCC is extremely limited; and there is an identified need to understand, develop, and implement PCC in China. The ten English language articles provided information on cultural understandings of personhood, operationalization and measurement of core concepts of PCC, and barriers and facilitators of implementing PCC in China. Across the literature, three articles identified the importance of and need for having PCC in LTC facilities in China (Wang et al., 2018; Zhao et al., 2016; Zhao, 2017). Four articles assessed LTC managers’ and employees’ knowledge of and attitudes towards PCC, showing that community health care providers, managers and staff tend to have positive attitudes towards PCC, but also demonstrating a relatively poor understanding of and a lack of skill competence towards PCC (Zhong & Lou, 2012; Wang et al., 2018; Wang et al., 2017; Kong, Fang, & Lou, 2017). Mao et al. (2016) used the Person-centered Care Assessment Tool (P-CAT) to assess the level of person-centeredness in LTC facilities in China and found that direct care staff rated organizational support for PCC as extremely low. Four articles adapted person-centered dementia care tools, including P-CAT (Zhong et al., 2013), Person-centered Climate Questionnaire-staff version (PCQ-S) (Cai et al., 2017; Yang et al., 2018), and staff-based measures of individualized care (IC) (Chappell & Chou, 2010), and
tested their validity and credibility. One article evaluated an educational intervention to promote community health care providers’ knowledge of and tendency to use a person-centered dementia care approach (Wang et al., 2016). We organized our analysis and synthesis of these articles into the following themes: Chinese cultural relevance of person-centered care, perceived needs for person-centered care for older adults in China, implementation and measurement of person-centered care in China, and person-centered dementia care model.

2.3.1 Chinese Cultural Relevance of Person-centered Care

Chinese culture can serve as a premise or facilitator for operationalizing PCC but some values and notions in Chinese culture can be barriers to applying PCC in China. In Confucian philosophies, interpersonal and social interactions are based on reciprocity, loyalty, benevolence, self-respect, self-control, and face saving (Wah & Tao, 2007). The Chinese concept of personhood emphasizes interpersonal transactions. It focuses on whether the individuals’ behavior fits or fails to fit the interpersonal standards of society and culture (Kong et al., 2017). Maintaining a long-term harmonious relationship with their caregivers is a basic expectation for older adults in China. An unstable or distrustful relationship with their caregivers will make them feel insecure, and therefore discourages them from expressing their needs and challenges (Liou & Jarrott, 2013). They also tend to value caregivers’ attitudes more than professional knowledge and
skills. Older adults would expect paid caregivers to be as supportive and caring as they would be to their own families (Wah et al., 2007). If caregivers fail to use verbal and nonverbal symbols perceived as supportive and caring, such as hand holding and smiling, older adults might become anxious, self-blaming, and reluctant to communicate with caregivers about their feelings and needs (Shih, 1996; Wah et al., 2007).

Chinese family values, and the social expectations of filial piety work together to place relationships at the very core, consistent with applying person-centered care in different care settings. It is a social obligation for them to provide their family in need with direct care at home or assistive care and supervision in LTC settings (Holroyd, 2001). Thus, incorporating the family in the plan of care and supporting their care is consistent with both Chinese cultural expectation and person-centered care. In traditional culture, Chinese strive to maintain harmony with nature, social institutions, and in human relationships. To be in harmony means to follow the expectations of “sincerity, loyalty, filial piety, and benevolence and to avoid negativism and emotional outburst” (Chen-Louie 1983 p. 200). Thus, Chinese older adults and caregivers tend to avoid direct confrontations and disclosures of personal difficulties within the family (Au, Shardlow, Teng, Tsien, & Chan, 2012). This may prevent them from directly expressing their feelings and dissatisfaction with significant others.
Traditional Chinese culture, particularly Confucianism, recognizes treating others with dignity as a core concept in thought and moral practice. It fully acknowledges one’s humanity, particularly those with cognitive challenges or functional limitations (Kong et al., 2017). It recognizes human dignity as realized through relationships and interactions between self and others, which echoes the values of person-centered care and the senses framework (Nolan et al., 2004). The Chinese term for dementia has negative connotations such as being confused and losing one’s mind or being catatonic, triggering social and individual stigma. This situation may also cause an individual and their family to lose face in interpersonal relationships (Dai et al., 2013). Despite the Confucianist mandate to respect the dignity of others, patients are seen as weak, dependent, and vulnerable persons, needing help and protection from their families (Kong et al., 2017). In contrast to the defining of the person in person-centered care, persons with dementia in Chinese culture tend to be regarded as patients who passively receive care from their formal or informal caregivers (Dai et al., 2013). This perception serves as a potential cultural barrier to acknowledging persons with dementia as valuable and competent persons who deserve opportunities to be engaged in meaningful social networking and make decisions for themselves.

2.3.2 Perceived Need for Person-centered Care for Older Adults in China

Studies offer evidence that person-centered care is valued by older adults in LTC
facilities and is much needed in China. We found that older adults in China value and desire autonomy, a sense of identity, meaning in life, and a sense of empowerment in LTC facilities, consistent with the core concepts of PCC. A study focusing on dignity and personhood in LTC facilities in Hong Kong found that older adults fear losing autonomy, personal independence, freedom and choice in LTC facilities (Wah et al., 2007). The author highlighted a profound need to maintain older adults’ human dignity through helping them to obtain a sense of identity and meaning in life. A study investigated the relationship among older adults’ perceived empowerment, social support, quality of life, and their lived experience in the LTC facilities (Wang et al., 2016; Wang et al., 2018). The findings identify multiple challenges facing older residents, including threats to their senses of belonging and dignity deriving from the care model, and facility culture that inhibit their ability to interact with other residents and staff in a personally-meaningful manner. Some older residents’ sense of belonging and dignity were threatened when LTC facilities put efficiency of care ahead of residents’ well-being. Residents expressed a strong desire for greater respect for their dignity, privacy, and personal values; They longed for a home-like environment where services and care were tailored to their personal preferences. They hoped to have more opportunities for social interactions and recreation within and outside LTC facilities (Wang et al., 2016). The study also found that older residents reported a significant lack of perceived
empowerment while a higher level of perceived empowerment from the care that they received is associated with a better self-rated quality of life (Wang et al., 2018). The study pointed out the importance of implementing PCC, which also was emphasized by one of the literature reviews in Chinese which suggested a need to develop a PCC model with culturally specific implementation approaches in China (Zhao et al., 2016).

### 2.3.3 Implementation and Measurement of Person-centered Care in China

Implementation of person-centered care in Chinese LTC facilities is just beginning to be studied systematically. Three articles addressed the staff/caregiver-based measurements of PCC in LTC facilities in China, advancing the ability to measure and conduct research on PCC. A staff-based scale related to individualized care for older residents in LTC facilities was introduced and validated in Hong Kong (Chappell & Chou, 2010). The tool includes four subscales that measure: staff perceptions of their knowledge of residents (Know scale); the general environment in which the staff work (Autonomy scale); staff communication with one another and supervisors within the LTC home (Communication-SS scale reflects); and staff communication with residents (Communication-SR scale). Results show that the tool is valid and can be used among caregivers in Hong Kong for both research and care purposes. Zhong et al. (2013) validated the Chinese version of P-CAT among 330 formal caregivers in 34 LTC facilities in a north-western city in China after translation, back translation, and adaptation of the
tool based on literature review and expert consultation. Results show that further study is needed to test the cultural sensitivity, reliability, and validity of the tool among Chinese caregivers in LTC settings. Mao et al. (2016) used P-CAT among 112 formal caregivers in 20 LTC facilities in Hunan Province, China. They found that caregivers’ age and educational background were positively associated with the P-CAT scores and called for hiring nursing aides who are younger and have a higher educational level. Yang et al. (2018) validated the Chinese version of PCQ-S in LTC facilities in Hunan, China. Cai et al. (2017) translated and validated PCQ-S tool in three hospitals in Yunan, China. The two studies showed that PCQ-S can be used to assess the person-centered climate in both nursing homes and hospitals in China with a good validity and reliability.

Several studies identified good practices towards and major barriers to implementing PCC in Hong Kong and mainland China. Zhong et al. (2012) explored person-centered care practices for older residents with dementia in LTC facilities in Hong Kong using Brooker’s four major elements of person-centered care to guide the interview. They interviewed 11 managers of LTC facilities in Hong Kong about their perceptions, daily practices, and barriers relating to PCC for older residents with dementia. They found that managers had varied and inconsistent understandings of person-centered care. Some put more weight on individualized care. Some viewed PCC
as a similar approach to holistic care. And others emphasized the importance of maintaining the dignity of persons with dementia. Good practices identified towards PCC are related to elements of VIPS framework: 1) valuing older adults with dementia and their caregivers as a stepping stone of practicing PCC; 2) individualized care as a mechanism of practicing PCC; 3) continuous assessment as a pathway to practicing PCC; and 4) nurturing environment as a facilitator in practicing PCC (Røsvik et al., 2011).

Inconsistency of the conceptualization of PCC, an underprepared workforce, high work stress and environmental constraints were reported as major barriers to integrating PCC in daily practices. One study conducted in mainland China assessed community health care providers’ dementia knowledge, attitudes, and care approaches (Wang et al., 2018). They found that community health care providers tended not to use a PCC approach in dementia care due to a lack of knowledge, support from organizations, and experience caring for persons with dementia. Two studies in mainland China identified lack of communication between staff and older residents and poor management support as major problems in providing PCC for frail older adults in China (Zhao et al., 2016; Zhao, 2017).

2.3.4 Person-centered Dementia Care Model

Findings were combined in an overarching model of person-centered dementia care in China (See Figure 3). The person with dementia is at the heart of the model,
thriving in interactions with all the persons who are involved in their care, which can be signified and evaluated by the achievement of favorable person-centered outcomes for the person, as well as from staff/managers and family caregivers, including senses of security, belonging, purpose, achievement, continuity, and significance (Nolan et al., 2004). Other PCC measures that were used and validated in the reviewed literature—such as P-CAT, IC, and PCQ-S—can also be adopted to evaluate PCC outcomes (Zhong et al., 2013; Cai et al., 2017; Yang et al., 2018; Chappell et al., 2010). Person-centered process—the next inner ring in the model of person-centered dementia care in China—supports the partnerships between persons with dementia and their care partners. Examples of person-centered process and practices include understanding care from the perspectives of the person with dementia, having sympathetic presence, sharing decision-making, and prioritizing well-being ahead of routines and scheduled tasks (Kong et al., 2017; Edvardsson, 2010; Fazio et al., 2018). The process is influenced by the shared understanding of core values and philosophies of person-centered care, which is currently lacking in China (Zhong & Lou, 2012; Wang et al., 2018; Wang et al., 2017; Kong, Fang, & Lou, 2017). The next ring is coordinated community where all persons involved in the care of a person with dementia openly communicate with one other. Our literature informed us that family is the most important unit within the community (Wah et al., 2007). Chinese family values and the social expectations of filial piety place
family relationships at the very core of the community. Thus, incorporating family in the plan of care and supporting family caregiving are the keys to building a coordinated community. Understanding of person-centered dementia care is never complete without taking culture and social values into consideration. Values and attitudes in the culture can serve as facilitators but can also be barriers to implementing person-centered care.

2.4 Discussion

Person-centered care has not yet been clearly conceptualized in China. In Chinese literature, it is more of an abstract concept in health care that is consistent with the value of building a harmonious society and promoting human-oriented outlook or development. PCC has not been clearly operationalized or applied in daily practices nor has it been included in quality of care evaluations in the Chinese literature. Among the four articles in the Chinese language literature that we included, two research teams collaborated with researchers in Western Europe and Australia to introduce and validate PCC measures in China and to assess the person-centeredness of LTC facilities using available tools. English-language literature discussed benefits of PCC, barriers to PCC, and introduced and validated self-rated caregiver-based tools that measure to what extent care staff rate their working setting and their care provided as person-centered for older adults. Person-centered dementia care has gained increasing attention from
researchers in China and the basic tenets of PCC are consistent with Chinese philosophy and culture but more studies are needed to define and understand it.

Understanding of PCC is never complete without taking traditional culture and social values into consideration. Chinese culture can serve as a premise or facilitator for operationalizing PCC in China, such as the concept of showing respect and treating others with dignity. However, some values and notions in Chinese culture can be barriers to applying PCC, such as the understanding of personhood, maintaining relational or family harmony at the expenses of communicating or expressing oneself (Kong et al., 2017a). Persons with dementia require a holistic, collaborative and ongoing understanding from their care partners of their needs and preferred self to maintain meaningful social relationships and achieve a sense of belonging and continuity (McCormack et al., 2006). Since family members have major roles in caring for persons with cognitive impairment in China, it is not only important to carry out research on helping formal caregivers to initiate effective communication, build relationships with and involving family members in the care but also to guide informal caregivers to resources, and support them in person-centered, relationship-based approaches to maintaining well-being.

The model of person-centered dementia care in China that we developed based on the literature review may provide a starting point to help operationalize globally-
important principles of PCC in specific socio-cultural contexts. It can also assist in understanding how the core of PCC—all persons involved in the care and their relationships—is influenced by the interplay of person-centered practices, shared understanding and value of PCC, and coordinated community and how all these factors connect to the family values, personhood, and filial piety in Chinese culture. The framework can be further developed by more empirical studies and evolve with the ongoing operationalization of PCC.

The increasing understanding and recognition of the value of person-centered dementia care is significant particularly due to the growing prevalence of dementia in China and globally. This bilingual literature review informed us that the core values of personhood, as understood in other countries, is consistent with personhood in China. For example, The Chinese concept of personhood emphasizes interpersonal transactions (Kong et al., 2017), consistent with the Senses Framework (Nolan et al, 2004) and Kitwood’s theory (1993). The review also helped us identify potential first steps towards understanding, developing, and implementing PCC in China, that is to distinguish PCC practice from an abstracted concept and to better understand it by conducting more empirical studies that examine globally-relevant PCC concepts with culturally specific approaches to gather information needed to provide PCC in China.
3. Living with Cognitive Impairment in China: Exploring Dyadic Experience through a Person-centered Care Lens

3.1 Introduction

China has experienced a substantial increase in the number of older adults with dementia and milder forms of cognitive impairment. In 2015, 8.18 million older adults in China were diagnosed with dementia; on average, over 360,000 new cases are discovered every year (Li et al., 2015). In addition, mild cognitive impairment (MCI), an intermediate state between normal cognitive aging (becoming increasingly forgetful) and dementia (Petersen et al., 2014; Vega & Newhouse, 2014) is strongly associated with an increased risk of dementia. The estimated prevalence of MCI and dementia among older adults in China was between 13% and 20% (Nie et al., 2011; Ding et al., 2015). MCI is a clinical entity. Its symptoms are not severe enough to meet the criteria for dementia but pathology can be developing in the brain. Although some MCI does not convert to dementia, it does have increased risk of progression to dementia. The progression of MCI does not follow a predictable and linear path. Thus, PWCI and their care partners tend to experience uncertainty in the extended period of cognitive function decline. Normally, persons with MCI do not have deficits in activities of daily living but MCI can negatively affect their memory, general knowledge, vocabulary, and thinking skills, such as abilities to complete complex tasks and make sound decisions. The major
challenges lie in the interpretation of the condition, uncertainty, minimizing the impact of the disease, and preparing to adapt to more changes.

Persons with cognitive impairment (PWCI) tend to experience distress, self-doubt, and depressive symptoms as their cognitive function declines and related symptoms progress, which can threaten their self-identity and self-esteem (Liu, Insel, Reed, & Crist, 2012). Living with cognitive impairment does not just affect those with the disease; it also has a profound impact on their family members. Most PWCI in China are community-dwelling and receive care and support from their family members in their homes (Dai et al., 2013; Wang, Xiao, & Li, 2018). Limited availability of residential care and community-based services and supports pose great challenges to PWCI and their family (Wittenberg & Hu, 2016; Wang et al., 2018).

Even though it is extremely challenging to provide care for those with advanced dementia, studies indicate supporting persons with MCI and mild dementia can be particularly difficult during the time period of extended cognitive decline (Spingate & Tremont, 2013). Person-centered care is the preferred way to approach dementia care and has become, in Western countries, the standard of care (Edvardsson et al., 2010). Evidence shows that person-centered care may reduce PWCI’s dementia-related behavioral symptoms (Edvardsson, Winblad, & Sandman, 2008). Thus, creating foundation for person-centeredness early in the disease is important. However, the
majority of studies neglect PWCI by exclusively focusing on family caregivers or only indirectly including PWCI’s characteristics (Cheng, 2017; Rolan & Chappell, 2015). Very few studies embrace dyadic variables or perceptions to understand how the change in cognitive function affects their life and their relationship from both sides (Bosco et al., 2018; Wawrziczny et al., 2016).

Among family care partners, a term that encompasses the support provided by family as well as physical care, spousal care partners typically play a primary role in supporting those with PWCI. When PWCI and their care partners are spouses, there may be changes in roles in the marriage and reshaping of their expectations from each other (Wawrziczny et al, 2016). Spousal care partners may experience different levels of stress and a sense of psychological well-being based on PWCI’s degree of cognitive impairment (Arbel, Bingham, & Dawson, 2019). They may experience more stress when their loved ones are at an initial stage of cognitive decline. Some studies discuss negative effects of living with dementia on the quality of their marital relationship (Wawrziczny et al., 2014; Ducharme et al., 2013) but failed to explore the positive aspects of living with cognitive impairment on the relationship.

Spousal care partners can support and empower PWCI to develop new coping strategies in daily life and work with them to find a balance between interdependence and independence together. This aligns with the core concepts of person-centered
dementia care (Kitwood & Bredin, 1992), that is to empower persons with dementia and value their personhood. Nolan’ senses framework shifts the focus of person-centered care from individual needs to the dynamics of their relationships (Nolan et al., 2004). It extends the belief that all stakeholders involved in caring should experience relationships that promote a sense of security, a sense of belonging (“to feel part of things), a sense of continuity (“to experience links and connections”), a sense of purpose (“to have goals to aspire to”), a sense of achievement (“to make progress towards the goals”), and a sense of significance (“to feel that you matter as a person”) (Watson, 2019. p560-561). In the context of dyadic relationship, having a sense of continuity means that care partners can maintain shared pleasures/meanings with PWCI in their relationship and communicate the expectation of care clearly and consistently with PWCI. PWCI and their care partners can use their shared experiences to contextualize present and future and sustain an interdependent spousal relationship. Experiencing a sense of significance means that PWCI can feel being recognized and valued as a person of worth whose actions and existence are of importance. To care partners, their sense of significance is strengthened when their commitment is valued and they experience an enhanced sense of self. Collectively in the context of dyadic relationships, a sense of achievement can be multi-dimensional but overall PWCI and their care partners should have opportunities to meet their meaningful and valued goals, to feel satisfied with their efforts (have done
the best that they can) and to experience self-growth in the process. A sense of security are essential physiological and psychological needs for PWCI and their care partners that they feel safe and free from threat and harm and they feel confident in their capabilities and in their resources of support. PWCI and their care partners gain a sense of purpose when they have a clear set of goals to aspire to and have opportunities to engage in activities that can help them to identify and pursue the goals. A sense of belonging is obtained when PWCI and their care partners do not feel that they are experiencing these alone and can form and maintain meaningful and reciprocal relationships and to feel being a part of a family, community, or friends group. The six senses are interrelated with each other in multiple ways. Relationship-centered approaches that foster the experience of these six senses can be conceptualized as a process of realizing person-centered care and a foundation to the well-being of PWCI and their care partners (Ryan, Nolan, Reid, & Enderby, 2008). The experience and sustaining of the six senses are made possible by person-centered care and in turn, facilitate person-centeredness in PWCI and their care partners’ day-to-day life through relationship-centered approach.

Being spouses of PWCI and living with them for several decades does not necessarily mean that it is easier for them to provide person-centered care and maintain a valued and healthy relationship. Care partners may overlook the changing needs of
their spouses as they assume that they know their spouses very well. Exploring successes and challenges to PCC, as operationalized by the Senses framework, in the context of PWCI and their spousal care partners early in the disease, may provide insights into how person-centeredness might be maintained throughout the disease course. Understanding how PCC occurs in the dyad also the key to identifying unmet needs as well as barriers and facilitators to improve their well-being.

Therefore, the purpose of the study is to explore and understand the dyadic experience of persons living with MCI and mild dementia and their care partners from a person-centered care lens in the social and cultural context of China, with a specific focus on how elements of PCC, as operationalized by the Senses framework, already operate or fail to operate in the context of persons living with dementia and their spousal care partners.

3.2 Methods

This study adopted a descriptive qualitative design. Each dyad is a case in the study.

3.2.1 Ethical Approval

We obtained the Institutional Review Board (IRB) approval from Duke University. Letters of support were obtained from Fudan University Affiliated Huashan Hospital and community agencies in Shanghai. Written informed consent from PWCI
their care partners were obtained by staff from Fudan University Affiliated Hushan Hospital.

### 3.2.2 Design

We used semi-structured open-ended interviews (Ashton, 2014) to explore the experiences and perceptions of PWCI and their care partner’s, regarding living with cognitive impairment, working with each other, communicating with each other and taking care of each other. We then applied the person-centered dementia care framework, and Nolan’s senses framework to the analysis of the interviews to understand their experiences and perceptions.

The Shanghai Aging Study is an ongoing epidemiological study that enumerates the prevalence, incidence and risk factors for dementia and mild cognitive impairment (MCI) among PWCI in an urban community of Shanghai, China (Ding et al., 2014). The larger study sampled 52 participants living with cognitive impairment from Shanghai Aging Study to make sure that persons with normal cognition, MCI, and mild dementia were included. We applied purposive and convenience sampling to select the subsample from the larger study to ensure that we have participants with MCI and mild dementia, that we have a bigger range of age differences, and that we have both males and females as care partners in the current study. Cognitive and physical function were clinically assessed and diagnosed as part of the epidemiological study, using valid and reliable
instruments; details are described elsewhere (Ding et al., 2014). Eligible participants were community-dwelling individuals who were diagnosed with MCI or mild dementia, understand Mandarin or the Shanghai dialect, and their spouses who self-identified as having the primary responsibility of caring for the individuals with cognitive impairment. A subset of 12 dyads of PWCI and their care partners (7 with MCI and 5 diagnosed with mild dementia) were selected for this study, excluding couples without cognitive decline. Information of these participants can be found in Table 2 (See Table 2).

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<th>Cognitive function</th>
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<td>Mild Dementia</td>
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<tr>
<td></td>
<td>CP1</td>
<td>Female</td>
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</tr>
<tr>
<td>2</td>
<td>CR2</td>
<td>Female</td>
<td>Mild Dementia</td>
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<tr>
<td></td>
<td>CP2</td>
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<tr>
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<td>Male</td>
<td>Mild Dementia</td>
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<tr>
<td></td>
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<td>4</td>
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<tr>
<td>5</td>
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<td></td>
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### 3.2.3 Data Collection

Interviews were conducted with PWCI and their care partners separately at their home or in a private room in a memory clinic based on participants’ preferences. Each
interview took from 50 minutes to 2 hours depending on the amount of information the interviewee wished to share. All interviews were digitally recorded.

The interview guide was structured to elicit a comprehensive description of daily life from the perspective of the PWCI and the care partner, with attention to care needs. Interviews began with the grand tour questions followed by probes. These questions served as guideposts with instructions for probing, validating, and transitioning between topics. Example questions are “Could you please tell me about a typical day of yours?”, “Can you tell me about how you perceive your relationship with each other?”.

3.2.4 Data Analysis

The interviews were first transcribed verbatim into Chinese by one team member and then proof-read to ensure accuracy by another bilingual team member. Transcripts were translated from Chinese to English. All the translations were conducted by a translator and then back translated by a master-level student from Asian and Middle Eastern Studies. All the Chinese and English transcripts were checked and validated before analyses. Transcripts were uploaded into NVivo 10 for coding and storage of data.

We used a directed content analysis (Hsieh & Shannon, 2005) to allow interpretation of data by drawing on the Senses Framework (Nolan, 2004), which enables us to extend and validate the framework using the empirical data. We adopted
a two-cycle coding approach (Saldaña, 2013). In the first-cycle, we developed a priori
codes from the Senses Framework. The team then added new codes to the coding book
to reflect experiences specific to PWCI and their care partners in this study based on the
questions and their narratives. New codes were discussed among the team members.
We focused on their dyadic perceptions and experiences, compared overlaps and
contrasts to enhance our understanding of the nature of their relationships and
experience. We met to discuss the coding decisions and reach consensus in the full
group. In the second-cycle coding, the coded texts were arranged into categories and
subcategories based on how they were related (Hsieh & Shannon, 2005). During
analysis, memos were kept to clarify coding decisions (Sandelowski, 1995). We referred
to the original quotations when we need more information and context. Eventually, we
synthesized the patterns based on our coding.

We adopted a cross-cultural analysis approach within the team comprising
bilingual researchers and English-speaking researchers. During the pilot coding, we
developed our coding schemes and codes in English through an iterative process,
during which, bilingual and English-speaking coders coded the Chinese and the
translated transcripts from three dyads and developed a set of first-level codes at regular
team meetings through extensive discussion. In the first-level coding, four coders started
with coding the Chinese and translated transcripts independently. We compared along
the way to see if the first-level coding and the extraction of categories and concepts were consistent. We keep summaries and memos of all the discussion among members of the cross-cultural team to keep track of the translation and interpretation. After reaching conceptual consistency between the coding of English and Chinese transcripts (Twinn, 1998; Chen & Boore, 2010), we coded the rest of the interviews (one quarter) in Chinese.

3.2.5 Rigor

Multiple strategies were used to establish qualitative rigor (Guba, 1981). For credibility, we engaged other team members so that those who did not participate in first-level coding can review and challenge our interpretations. To further ensure confirmability, we held frequent meetings to discuss definition of the codes and the coding. We compared our coding patterns to ensure that the interpretations were sound. Rich descriptions of the cases (each dyad is a case) with the use of quotes of participants were considered to contribute to transferability in qualitative research. For dependability, we kept summaries and memos of all the discussion among members of the cross-cultural team to keep track of the translation and interpretation. The refinement of the codes and themes were discussed by the whole team, which facilitated joint decision making between bilingual and English-speaking team members on the coding schemes and categorization of coded data.

In terms of the timing of translation in cross-language qualitative research, there
are emerging suggestions of “late-phase translation” (p.136) of excerpts, whereby researchers keep quotations in the original language as long as possible (Santos, Black, & Sandelowski, 2015). By contrast, others argue for translating interview data at an earlier stage of the analysis to allow a more interactive process of data analysis with researchers who do not speak the source language (Chen et al., 2010). We coded all the transcripts in Chinese to stay in the original language as long and as much as possible. We also acknowledged the advantage of having transcripts translated to English and had the coding system in English when working in a multi-national and multi-cultural team. During the pilot coding, we developed our coding schemes and codes in English through an iterative process where bilingual and English-speaking coders coded the Chinese and the translated transcripts from three dyads and developed a set of first-level codes at team meetings through extensive discussion. We compared along the way to see if the first-level coding and the extraction of categories and concepts of Chinese and translated transcripts were consistent using features of NVivo. We kept a record of discussion on translation and understanding of the narratives between bilingual researchers and English-speaking researchers was useful to make the development of the interpretations transparent. We translated all the emerged categories, concepts, themes, and quotes into English and found that coding and extraction of themes were consistent during the analysis of the data, whether using Chinese or English transcripts
(Twinn, 1998; Chen & Boore, 2007).

3.3 Findings

In this study, the participants’ experience of the six senses emerged out of the dynamics between PWCI and their care partners. In our study, we first interpreted the experience of the six senses through the couples’ dyadic relationship and then we considered the influence of the socio-cultural context.

3.3.1 Experience of Well-being

3.3.1.1 A Sense of Achievement

A sense of achievement, which is a key component of wellbeing, emerged from the dynamics of the couples’ daily interactions. Some care partners experienced a sense of achievement when the PWCI and/or others acknowledged that they had provided good care in words or in actions. PWCI and care partners also experienced a sense of achievement when they perceived themselves as “not being a burden” to each other or to their adult children and “being able to help”. One care partner (CP3) told the interviewer about her husband that,

“He is an introverted person and does not know how to express himself well. He just would not say it to me, but he told his sister that I treated him very well and I am a good wife. His sister told me about it and I complained to her that he never praised me directly. He expresses his gratitude in action. He would insist
helping me with the chores even though I told him to take a rest.”

When being asked about helping his wife with housework at home, the husband (CR3) mentioned that,

“My wife works hard to take good care of me and our home. I cannot help much. But I believe if I do a bit more of the chores, she could do a bit less.”

Another care partner’s (CP2) wife (CR2) was diagnosed with MCI for three years by the time of our interview. The wife had been taking charge of housework for the past 50 years and she was still doing so after the diagnosis (CP2). The care partner (CP2) used acknowledgment as a powerful way of motivating and encouraging his wife (CR2) to remain engaged in housework and other daily activities in order to maintain her cognitive and physical function. He told the interviewer that: “I praise her often. I tell her that she does it so well, much better than I do. And she looks very happy, like a child.” The wife (CR2) told us that: “I don’t need much help. I am good at housework. Sometimes my husband cleans the table after dinner. I always reclean it because I clean it much better than he does. He admits it. You can ask him.”

Their sense of achievement also emerged from their shared experiences, such as their past achievements, achievements of their adult children or grandchildren. Having children who care about them and come to visit them frequently contributed significantly to their sense of achievement and vice versa.
PWCI tended to sense a lack of achievement when they were not as good at things as they used to be, particularly when they perceived this as a result of their diminished cognitive function. One participant (CR4) was 53 years old at the interview and was diagnosed with early-onset dementia. He had lived with his wife (CP4) and son in the neighborhood for over 20 years. He stated that,

“I was a very capable person. I worked as a driver and I was very familiar with this area. I don’t need any map or GPS. But now I get lost in my neighborhood. My brain degenerated. I was good at sewing. People in the neighborhood all know about it. They always asked me to make pillow cases and table cloth for them and I was happy to do it. But it has been getting harder for me to focus since I had this problem [pointed to his head].”

3.3.1.2 A Sense of Security

Multiple threats to a sense of security emerged for PWCI and their care partners. Increasing manifestations of dementia-related behavioral symptoms pose a potential threat to home or individual safety. Thus, some care partners had to focus almost all the attention on PWCI. There are role conflicts and sacrifice of their own interest and social life. Ensuring someone’s sense of security seems to come at the expense of other needs.

One care partner (CP5) said that,

“My life is all centered on him now. I dare not leave him alone at home. One
day I was out doing some grocery shopping. When I came back home, the kitchen was full of smoke. He totally forgot that he was steaming buns in the kitchen and left the stove on. The water was burned out and the steamed buns were like charcoal. I have no choice but to be with him all the time. I love participating in recreational and sports activities and I have been playing Mulan boxing for 20 years, but I had to give it up because I need to take him with me wherever I go.”

The husband (CR5) perceives his care partner (CP5) as a source of a sense of security: “When I have difficulties, I just tell my wife and discuss with her. Anyway, the first person that comes to my mind is her when I need help. I turn to her for help and she is there to help me.”

Some care partners expressed their lack of sense of security due to the abuse that they experienced in forms of neglect, emotional abuse including verbal assault and humiliation, and physical abuse such as throwing bowls or cups to the direction of the care partner that occurred as PWCIs’ character and personality changes progressed.

They had the awareness that the dynamics of caregiving capacity versus caregiving burden were shifting towards reduced capacity and more need. The lack of support from other family members and underdeveloped long-term care system further decreased their sense of security. Some participants believed that eventually they would need formal long-term care but they also pointed out that they were concerned about a
lack of quality and quantity of care, unprepared workforce and threat to personhood and dignity of persons with cognitive impairment in residential care facilities. One care partner (CP2) told the interviewee that,

“I can take care of her now but eventually we need to relocate to nursing homes. It costs a lot to live in nursing homes with good facilities and those nursing homes are usually located in suburban areas far from the city. There are some good and affordable public nursing homes, however, they all have a long waitlist. I visited a few nursing homes last year. You cannot conveniently receive medical care within the nursing homes because they do not have enough doctors or nurses. I remember two older adults just sat in the small room, doing nothing. No one talked to them nor did they talk to each other. There was no light in their eyes. I told myself, I cannot live my life like this.”

3.3.1.3 A Sense of Purpose

Some PWCI and their spouses tended to sense a lack of purpose as they grew older or after their children or adult children move out from their house because they were less engaged in meaningful activities or social networking. Even though they might have lowered their expectations, most participants do recognize meaningful things in their life as taking good care of themselves, providing the best possible care for each other, and not being a burden to their family. These serve as motivators and goals in their daily life.
The dyads’ sense of purpose is defined in the relation to each other but in certain circumstances, care partners’ achieving of a sense of purpose could jeopardize the sense of control for PWCI.

One care partner (CP11) has a folder of documents, in which she keeps detailed records of her husband’s clinic visits, test results and medications. She provided the perceived best possible care for her husband by improving his medication adherence, managing his diet, and actively communicating with the health care provider. However, her husband (CR11) statement showed that there was difficulty operationalizing PCC in their daily interactions.

“She takes very good care of me, but too good. What I should eat and what I should do are planned by her. She is confident that she understands me well and knows what is best for me. Sometimes I don’t like how things are planned for me.”

One care partner (CP2) regards himself as the “brain” of the dyad and is responsible for making plans and arrangements. He believes that “practice makes perfect” and this also applies to maintaining his wife’s cognitive function. Thus, he forced his wife to do calculation and solve Math questions at elementary school level in order to fulfill his purpose of “exercising her brain” and slowing down the progression of her cognitive impairment, which made his wife frustrated. His wife told the
interviewer that,

“I hate doing the math. I am not a child and it frustrated me. I am only doing it for him.”

3.3.1.4 A Sense of Significance

PWCI and their care partners showed their concerns and worries about each other. While care partners worried that no one can take good care of their spouses after they pass away, PWCI also showed concerns about how their care partners’ chronic conditions would be managed after their memory got worse. They obtained a strong sense of significance by perceiving themselves as playing key roles in providing care for each other.

One participant (CR2) said that,

“His disease is annoying, diabetes, he would have problems with his feet, eyes and even kidney eventually. I have been managing his diet and do not let him eat too much sugar. My brain is not working well sometimes. People say that my memory will get worse and worse. He is always worried about me but I was thinking to myself, who is going to care for him after my memory gets worse.”

Her husband (CP2) stated that,

“She might live longer than I do because she is younger and more physically active. I function as the brain and arrange things for her now. But who can do
this for her after I die?”

The dyads tend to experience a stronger sense of significance when they perceive themselves as pursuing their goals of providing good care or being helpful. Some PWCI choose to protect their care partners’ sense of significance. One care partner (CP9) is focused on searching for and purchasing supplements with ingredients that he believes are “good for memory and human brain” for his wife (CR9). Some of the supplements are even false advertised to be able to treat Alzheimer’s Disease. But the husband regarded himself doing the most significant thing to slow the progression of his wife’s cognitive decline.

“I know those supplements are useless but I decide to take them anyway and not to stop him from doing so because I know this would make him happy and fulfilled.”

3.3.1.5 A Sense of Belonging

Participants experience a sense of belonging within their home and at a community level when they perceive themselves as forming and maintaining valued and reciprocal relationships with others. They experience a sense of belonging when feeling that they are in good care and loved. One care partner (CP6) stated that:

“He always gets nervous when I am sick, even just with a common cold. Last month, I had a back pain, I said it was OK but he insisted taking me to the
hospital for a check. My grandson also got nervous and called several times asking how I am doing and telling me not to lift heavy things. Nothing to worry about, they just get nervous [smile].”

The experience of a sense of belonging is based on their healthy relationship, shared understanding, values, and goals for life. When there is a difficulty in communication or disparities in understanding, their valued and reciprocal relationships might be challenged. One care partner (CP8) said that,

“We have difficulty communicating with each other as he gets irritated easily. He is bad-tempered and unreasonable now. He always blames me and does not understand how difficult my life is now. People say talk to him, but how, he would not listen to me. He is not interested in talking with me.”

Her husband (CR8) stated that,

“I don’t have difficulty in my daily life. I don’t need help from her [his wife]. I am doing good. We are doing good. I handle my life well and she does her job at home. She is getting a bit slow but we are all right, much better than some other people at our age.”

At a community level, some participants moved out from their old community in the center of the city to apartments in outer city at a later stage of their life. Some moved because their old apartments no longer exist due to rapid urbanization and new city
planning. With the support from their adult children or by renting out their old apartment in downtown, some relocated to more accessible and newer apartments with elevators in suburban areas. And some others relocated because their grandchildren need to live in their apartments in downtown for their convenience of work commute. The relocation had profound influence on their social networking, daily routines, engagement in activities, and eventually on their sense of belonging. Statements such as “Not knowing the new neighbors well”, “Do not have much to talk to the people in the new community”, “Not familiar with staff working in the neighborhood committee”, and “Missing old friends in the old community” showed their lack of sense of belonging in the new community.

### 3.3.1.6 A Sense of Continuity

Experiencing a sense of continuity is related to the contextualization of present and future, involvement in care, maintaining of shared pleasure, and the normalcy of life within the established relationship with known people. The dyads’ sense of continuity is perceived in the relation to each other. When there is an imbalance between increased caregiving burden and reduced caregiving capacity, the continuity of care partners’ social networking or engagement in regular exercise or activities would be comprised. If there is no other source of support to be used, the situation is likely to get worse.
PWCI’s dementia-related behavioral symptoms and the stigma associated with dementia tend to change others’ perceptions of their personhood and some choose to no longer involve the couples in their social activities. Even though they still regard the PWCI and their spouses as their friends, family, and colleagues, it is difficult to involve them in some of the activities when extra support is needed to guarantee individual safety. Care partners may have to reduce their contact with friends and relatives and give up some of their activities or hobbies to adapt to the changes in their life.

One couple (CR7 and CP7) planned to move to Australia to live with the husband’s child to help take care of his grandson eight years ago. However, the wife was then diagnosed with MCI. The husband decided to stay in China with his wife and care for her. This care partner (the husband) stated that,

“Her memory is getting worse now, and her brain doesn’t work well, so I take her with me wherever I go. At home, I can’t sit down and do my own things. There would be troubles if I don’t watch her. To be frank, I have a lot of hobbies. I like photography. There used to be a photography class for elders, and I attended it every week. The pictures I took look great. I also travelled a lot. Now I participate in significantly less activities since she suffered from this illness. All my activities are centered around her. I tried to figure out some way so I can do things that I’m interested in and have her with me as well. I invited some of my
old friends who were physically healthy to go out together. I took photos for
them and they helped to take care of my wife. But we can rarely do it now since
her condition is getting worse.” on the other hand, the wife (CR7) experienced a
lack of sense of continuity at first but then she managed to change her way of
thinking and gained a sense of newly-perceived continuity. She said that,
“I used to work in the neighborhood committee and I am good at
communicating with others. I was very independent and took charge of
everything in the house. But my brain does not function well now. He takes care
of me mainly. He accompanies me to pick up medicine and see doctors. He
decides what [we] eat and what [we] buy. I did not feel good about obeying him
at first. But I told myself that I can only rely on him. It is all about taking care of
each other at this age. (He) treats me well, as a laolai ban (a companion at an
older age).”

3.4 Discussion

The current study explored PWCI and their spouses’ dyadic experiences of living
with cognitive impairment through a person-centered care lens. The Senses Framework
(Nolan et al., 2004) posits that high-quality care emerges from the quality of the
relationships that a person living with dementia experiences. Our study findings
support this framework, providing examples of how PWCI and their spouses’ experience of the senses relates to their wellbeing or lack of wellbeing.

By using a dyadic lens, we identified the importance of the bidirectional relationship of caregiving. Specifically, while care partners provided care for PWCI, PWCI also provided care for the care partners. PWCI obtained a sense of significance by perceiving themselves as persons of worth who can help and not being a burden to their family and their care partners. Where care partners and PWCI experienced well-being through the sense, the relationship was not a unidirectional relationship of caregiving and care receiving. It is more of an interdependent and reciprocal relationship, whereby spouses were care partners who worked with them, instead of worked for them to adapt to the changes in life as a couple. When care partners tended to provide too much care for PWCI, PWCI reported feeling less empowered in their own life. It is possible that this latter behavior emerges in part from the concept of patient-hood in Chinese culture that persons with illnesses are weak, dependent, and vulnerable, and that their close family should take good care of them and arrange their daily activities to conserve the patients’ energy (Kong et al., 2017). This perception is a potential cultural barrier to recognizing PWCI as competent persons who deserve the right to be involved in social activities and decision-making.
Person-centered care processes are a means of establishing and nurturing the healthy relationships between PWCI and their care partners. Our findings suggest that PWCI and their spouses experience the six senses through the person-centeredness in their daily interactions with each other. Maintaining a harmonious relationship with their care partners is expected in Chinese culture. The implications of this expectation in the context of cognitive impairment is an important gap in our empirical knowledge. Our findings indicated that, in some PWCI’s eyes, care partners’ good attitudes and gestures, comforting tones and other verbal and non-verbal symbols can be perceived as more important than the actual care that they receive. It makes them feel secure and obtain a sense of belonging. Otherwise, they would doubt themselves and feel reluctant to express their needs. An opportunity for further study would be to identify culturally-relevant approaches to supporting communication patterns that can not only convey acknowledgement of one’s commitment but also send alert on behaviors that have negative effects on their relationships. In our study, PWCI and their spouses experienced a sense of achievement when their efforts were well acknowledged through verbal or non-verbal communication. On the other hand, their experience of well-being was threatened when they failed to communicate their feelings with each other.

PWCI and their spouses who were able to do with, instead of doing for, and care about each other, rather than care for, described experiencing senses and a greater sense
of well-being. This finding is consistent with the core concepts of personhood in person-centered care, whereby supporting a PWCI’s personhood in an authentic relationship requires focusing on the interactions rather than the symptoms or caring tasks (Kong et al., 2017; Edvardsson, 2015; Fazio et al., 2018).

Our findings suggest that PWCI and their spouses’ experience of wellbeing also are influenced by their interactions and relationship with other family members, such as their adult children and grandchildren. The perceived significance of family and strong family responsibility embedded in the culture can put them at disadvantage when PWCI and their care partners intend to avoid direct conflict with and disclosure of challenges to each other and other family members. They are also reluctant to reach out to seek help and support from other family members in order to avoid being a burden. At the community level, rapid urbanization and relocation have a profound impact on their social networking pattern and senses of belonging and continuity.

3.5 Limitations

The current study has several limitations. First, we did not capture PWCI and their spouses’ changing experience overtime; future research should explore how these dynamics change or evolve over time, especially in relation to changing cognitive function with longitudinal data. Second, the participants all lived in an urban area, which may differ significantly from older adults’ experience in underdeveloped areas in
China. Given other research of the health disparities between urban and rural areas in China (Wu, Yue, & Mao, 2015), this would be an area for future research, as well.

Finally, other family members are not included in the current study.

### 3.6 Conclusions

The current study explored how elements of PCC, as operationalized by the Senses Framework, operate or fail to operate in the dyadic experiences of PWCI and their spousal care partners within the socio-cultural context of China. Person-centered care processes are a means of establishing and nurturing the healthy relationships between PWCI and their care partners. Our findings suggest that PWCI and their spouses experience the six senses through the person-centeredness in their daily interactions with each other. It also indicated successes and challenges to being person-centered early in the disease and identified their unmet needs as well as barriers and facilitators to improve their well-being.

4.1 Introduction

A total of 47 million people worldwide live with dementia, and 60% of them live in low- and middle-income countries (LMIC) (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). The number is projected to increase to 152 million in 2050. The fastest growth of this population is taking place in China, with the total number reaching 8.18 million (Wimo et al., 2017; Li et al., 2015). The number will be greater if we take mild cognitive impairment (MCI) into account, which is an intermediate state between normal cognitive aging and dementia; and is strongly associated with an increased risk of dementia (Petersen et al., 2014; Vega & Newhouse, 2014). The estimated prevalence of MCI and dementia among older adults in China is between 13% and 20% (Nie et al., 2011; Ding et al., 2015).

Most persons with cognitive impairment (PWCI) in China live at home and receive primary care from their family care partners, a term that encompasses the support provided by family as well as physical care (Dai et al., 2013; Chiu, Yu, & Lam, 2010). Spousal care partners typically play a primary role in supporting PWCI due to shrinking family sizes and increasing numbers of adult children moving away from their family for employment (Peng & Wu, 2015). Family care partners of PWCI have a
high risk of developing affective disorders such as major depression and anxiety disorder (Chien et al., 2011).

Providing long-term care for PWCI at home has a tremendous impact on the whole family functioning and dynamics (Li & Murray, 2015). Supporting PWCI can be particularly difficult during the time period of extended cognitive decline (Spingate & Tremont, 2013). There may be changes in roles and relationships in their marriage and reshaping of their expectations of each other (Wawrziczny et al, 2016). Provision of care may increase restriction and eventually take over the life of care partners, resulting in a missing of the self and loss of identity (Tuomola, Soon, Fisher, & Yap, 2016). There is a growing emphasis on the nature of the relationship between PWCI and their care partners in interpreting the experience of the dyads (Watson et al., 2019; La Fontaine et al., 2014). Some studies discuss negative effects of living with dementia on the quality of their marital relationship (Ducharme, Kergoat, Antoine, Pasquier, & coulombe, 2013; Wawrziczny et al., 2016) but failed to explore the positive aspects and the dynamics of their relationships from a longitudinal perspective.

Experience of PWCI and that of their spousal care partners are dynamic in the sense of their progressive conditions, changing perceptions of their personhood, and the nature of their relationships (Edvardsson et al., 2010). They tend to have different experiences at different stages of the progressive illness process (McKeown, Clarke,
Ingleton, Ryan, & Repper, 2010). It may be difficult to place PWCI in a specific stage as stages may overlap but the trajectory of their cognitive decline and increasing behavioral and psychological symptoms of dementia are noticeable (Jing, Willis, & Feng, 2016). At the beginning stage of MCI, they have increased forgetfulness, difficulty concentrating, and might have difficulty finding the right words (Adams, 2006). Their care partners start to notice the changes and experience the effects of the changes on their life and relationships. As their cognitive function and their ADL and IADL abilities continue to decline, they tend to have difficulty completing complex tasks and start withdrawing from family or friends as they have more challenges socializing. Their care partners need to take on greater responsibility, provide more assistance and adapt daily routines. At mild and mid-stage of dementia, their behavioral and psychological symptoms of dementia become more prominent (Reamy, Kim, Zarit, & Whitlatch, 2011). They have increasing memory deficiencies and need assistance to complete their daily living activities (Jing et al, 2016). These changes are difficult for both PWCI and their care partners. Both can experience grief as a response to their losses. Care partners’ increasing caregiving burden and the distress of managing PWCI’s behavioral problems can make them vulnerable to physical and psychological health problems (Blandin & Pepin, 2017). Even if the condition of PWCI stays relatively stable, they and their care partners are still likely to experience ups and downs in the long journal of developing
partnerships in living with cognitive impairment (Liu, Insel, Reed, & Crist, 2012). However, the majority of the current qualitative studies focused on a specific stage of dementia. Very few qualitative studies explored the trajectories of care partners’ experiences of providing care for PWCI retrospectively but did not adopt a prospective and longitudinal method and failed to explore and discover the trajectories of their experiences (Ducharme et al., 2013).

Nolan’ senses framework (Nolan et al., 2004; Liu et al., 2012) extends the belief that all stakeholders involved in PCC should experience relationships that promote a sense of security, a sense of belonging (“to feel part of things), a sense of continuity (“to experience links and connections”), a sense of purpose (“to have goals to aspire to”), a sense of achievement (“to make progress towards the goals”), and a sense of significance (“to feel that you matter as a person”) (Watson, 2019. p560-561). Relationship-centered approaches that foster the experience of these six senses can be conceptualized as foundational to the well-being of PWCI and their care partners (Ryan, Nolan, Reid, & Enderby, 2008). Each family has its own history of relationships, roles and experiences that can affect how PWCI and their care partners react to the diagnosis, make sense of the changes, and perceive a presence or absence of senses. They may experience a lack of shared pleasure with each other or experience increasing challenges of maintaining meaningful and reciprocal relationships with each other as PWCI’s cognitive function
declines (La Fontaine, 2014). PWCI may feel less recognized and valued as a person of worth as their ADL and IADL abilities decrease with the progression of dementia and their sense of personhood is threatened (Lorenz et al., 2019). Nolan’s senses framework and the philosophy of person-centeredness help us to interpret and understand facilitators of and barriers to PWCI and their care partners’ wellbeing throughout the trajectory. Person-centered concepts embedded in the provision of care can facilitate the experiences of positive aspects of caregiving and improve spousal relationships (Lloyd, Patterson, & Muers, 2016). The act and the acknowledgement of their giving and commitment are identified by Nolan et al. (1994) as a core domain of positive aspects of caregiving and satisfaction, which can lead to senses of purpose and achievement. These positive experiences are the key to adapting to changes in the journey and improving their reciprocal partnerships (Carbonneau, Caron, & Descroisiers, 2010). However, few articles have focused on negative and positive aspects of living with cognitive impairment through PWCI and their primary care partners’ dyadic experiences (Lloyd et al., 2016).

Being spouses of PWCI and living with them for several decades does not necessarily mean that it is easier for them to provide PCC and maintain a valued and long-term healthy relationship. Care partners may overlook the changing needs of their spouses as they assume that they know their spouses too well. Exploring challenges to
PCC over time, as operationalized by the Senses framework, in the changing context and dynamics of their experiences and relationships, may provide insights into how person-centeredness might be maintained throughout the disease course. Therefore, the purpose of the study is to explore and understand the changing dyadic experience and relationships of PWCI and their care partners from a person-centered care lens, through their navigation of living with cognitive impairment over time.

The majority of the current studies focus exclusively on caregivers. But researchers also realized the importance of taking both PWCI and their care partners into the picture when trying to explore their relationships (Braun et al., 2009; Fontaine & Oyebode, 2014; Wadham, Simpson, Rust, & Murray, 2016) and apply interventions (Ingersoll-Dayton et al., 2013; Whitlatch, Judge, Zarit, & Femia, 2006). These studies agree that the care for PWCI is transferring from individual-oriented to family-oriented and relationship-oriented care. One qualitative study adopted a longitudinal design to examine the influence of the diagnosis of dementia by comparing couples’ narratives at two weeks and at twelve weeks after the diagnosis and found that it is a gradual process of realizing the meaning of the diagnosis (Vernooij-Dassen et al., 2006). The current study is among the first prospective longitudinal qualitative studies to embrace dyadic interactions and relational variables to understand PWCI’s and their care partners’
experiences of living with cognitive impairment and the long-term impact on their relationships through a person-centered care lens.

4.2 Methods

4.2.1 Ethical Approval

We obtained Institutional Review Board (IRB) approval from Duke University and Fudan University Affiliated Hushan Hospital. Letters of support were obtained from Fudan University Affiliated Huashan Hospital and community agencies in Shanghai. Written informed consent from each PWCI and their spouses were obtained by staff from Fudan University Affiliated Huashan Hospital.

4.2.2 Design and Sample

We conducted a longitudinal qualitative study of a subset of 6 dyads of PWCI and their care partners over three years with three data collection time points (2015 to 2017). Information of these participants can be found in Table 3 (See Table 3).

Qualitative longitudinal research (QLS) is a general term referring to a variety of methodological designs. A fundamental characteristic of QLS is that the same sample of participants is interviewed more than once (Fadyl, Channon, Theadom, & McPherson, 2016; Thomson & Holland, 2003). Time is designed into the research process of QLS, making change a key focus for analysis.

We employed the approach of prospective QLS in this study (Saldaña, 2013). It is
potentially an approach to capture the complexities of relationships, experiences, and the impact on health policy (Thomson & McLeod, 2015). It offers valuable insights into how changing environmental and psychosocial contexts can influence personal experiences over time (Thomson & Holland, 2003). Therefore, prospective QLS is appropriate to exploration of the changing experience and relationships of PWCI and their care partners over time.

Participants were drawn from a larger study of living with cognitive impairment in China. The larger study sampled 52 participants from an ongoing epidemiological study “Shanghai Aging Study” (Ding et al., 2014), using purposive and convenience sampling to make sure that persons with normal cognition, MCI, and mild dementia were included in the study. At the first interview, we applied convenience sampling to select the subsample from the larger study so that we can ensure the feasibility of data collection. We also used purposive sampling so that we have participants with MCI and mild dementia, that we have a bigger range of age differences, and that we have both males and females as care partners in the current study. Two participants passed away after the first interview. I included six dyads in the study that we successfully followed at the second and the third interviews to ensure that I have participants whose cognitive function changes over time and whose cognitive function stays relatively stable, that I have both males and females as care partners, and that I can complete the data collection.
at the budget and time allowed. Participants’ cognitive and physical function were clinically assessed and diagnosed as a part of the epidemiological study, using standard criteria via consensus diagnosis. Eligible participants were community-dwelling individuals who were diagnosed with MCI or mild dementia, understand Mandarin or the Shanghai dialect, and their spouses who self-identified as being their primary caregivers. In this study, one dyad is regarded as one case and one case is a basic unit for analysis.

Table 3. Characteristics of Participated Dyads (over time)

<table>
<thead>
<tr>
<th>ID</th>
<th>Gender</th>
<th>Cognitive function (ADL-Barthel Index)</th>
<th>Time 1 age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>CR1</td>
<td>Male MCI (90)</td>
<td>MCI (90)</td>
</tr>
<tr>
<td></td>
<td>CP1</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>CR2</td>
<td>Female MCI (100)</td>
<td>Mild dementia (90)</td>
</tr>
<tr>
<td></td>
<td>CP2</td>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>CR3</td>
<td>Female MCI (95)</td>
<td>Mild dementia (75)</td>
</tr>
<tr>
<td></td>
<td>CP3</td>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>ID</td>
<td>First Name</td>
<td>Gender</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>----</td>
<td>------------</td>
<td>--------</td>
<td>-----------</td>
</tr>
<tr>
<td>4</td>
<td>CR4</td>
<td>Male</td>
<td>Mild dementia (75)</td>
</tr>
<tr>
<td></td>
<td>CP4</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>CR5</td>
<td>Male</td>
<td>Mild dementia (95)</td>
</tr>
<tr>
<td></td>
<td>CP5</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>CR6</td>
<td>Female</td>
<td>MCI (85)</td>
</tr>
<tr>
<td></td>
<td>CP6</td>
<td>Male</td>
<td></td>
</tr>
</tbody>
</table>

**4.2.3 Data Collection**

We conducted three interviews with each of the six dyads from 2015 to 2017 (36 interviews in total). In this study, one dyad is regarded as one case and one case is a basic unit for analysis. At baseline in 2015, interviews were conducted with PWCI and their care partners separately at their home or in a private room in a memory clinic based on participants’ preferences. At time 2 and time 3 (2016 and 2017), PWCI and their care partners were interviewed at their home separately. Each interview took from 50 minutes to 2 hours depending on the amount of information the interviewee wished to share. All interviews were digitally recorded and transcribed.

The interview questions for baseline data collection (See Appendix A) were
informed by the purpose of the study and some quantitative information from the questionnaires of the larger study. We aimed to explore PWCI and their care partners’ dyadic experiences and interactions, thus, they dyads were asked to provide a comprehensive description of their life and daily activities with details on difficulties and challenges facing them, help available to them and help needed but not available to them. The dyads were also asked to share their feelings of receiving care and/or providing care. The care partners filled out a questionnaire investigating their social networks and relationships before the interviews. Therefore, we also included questions regarding how they interacted with persons that they listed in different closeness with them.

Questions of the follow-up interviews were informed by the information gained from the first interviews, the Senses Framework (Nolan et al., 2004), and the purpose of the study. In order to capture the changes of their experiences, we maintain the consistency of the main questions so that we can keep track of the changes during the analysis. We also asked them about their perceptions of the changes happening to them. During the interview, the first author first provided a very brief summary of the key points from the last interview and asked the participants to reflect on it and then asked the participants about how they perceive and respond to specific difficulties and challenges that they mentioned at last interview to focus on processes and changes
rather than just snapshots at multiple time points. The first author referred to the case summary and tailored questions for follow-up interviews by drawing upon the story of the dyads and what was previously discussed at baseline. For example, in case 2, I asked the wife about her husband insisting on having her solve elementary-level maths questions and housework at the follow-up interviews. I also asked her about going to her taichi class as a question regarding her daily life. I asked the husband about his tea party and his work in engaging his wife in housework and solving maths questions. I was able to track the changes in the wife’s ADL and IADL abilities and their social networks through the tailored questions. We also added questions regarding their spousal relationships and the way of expressing their positive and negative emotions. Based on the dyads’ narratives, recap and comparison with the last interview, the interviewer captured the changes over time.

4.2.4 Data Analysis

A total of 36 interviews with the 6 dyads from 2015 to 2017 were transcribed verbatim into Chinese by one team member and then proof-read to ensure accuracy by another bilingual team member. Each dyad’s narratives are regarded as a case in the study. Transcripts were uploaded into NVivo 11.0 for coding and storage of data. During the analysis of the baseline interviews, coders started with coding the Chinese and translated transcripts independently. We compared the first-level coding using
Chinese and translated (English) transcripts and found that the extraction of categories and concepts were consistent between analysis of transcripts in two different languages. We keep summaries and memos of all the discussion among members of the cross-cultural team to keep track of the translation and interpretation. We reached conceptual consistency between the coding of English and Chinese transcripts (Twinn, 1998; Chen & Boore, 2010). Therefore, we coded all the transcripts of the time 2 and time 3 interviews in Chinese to stay in the original language as long and as much as possible (Santos, Black, & Sandelowski, 2015). We also had the coding system in English and translated all the emerged categories, concepts, themes, and quotes into English to work within a cross-cultural team (Twinn, 1998; Chen & Boore, 2007).

There is no systematic or universal approach for analyzing QLS (Saldana, 2003). Rich and multi-dimensional data produced by qualitative longitudinal research require innovative strategies for data analysis, interpretation and display (Thomson et al., 2015). We analyzed the interviews both cross-sectionally and longitudinally.

We used a directed content analysis (Hsieh & Shannon, 2005) to allow interpretation of data by drawing on the Senses Framework (Nolan, 2004). We adopted a two-cycle coding approach (Saldaña, 2013). In the first-cycle coding, we developed a priori codes from the Senses Framework. The team then added new codes to the codebook to reflect experiences specific to PWCI and their care partners in this study.
based on the questions and their descriptions. The team discussed new codes and reach consensus on adding them to the codebook or not. We focused on their dyadic perceptions and experiences, compared overlaps and contrasts to enhance our understanding of the nature of their relationships and experience.

When the coding of each case at different interview times was completed, longitudinal analysis began. We aimed to understand PWCI and their care partners’ experiences over time and their reactions to it. We first identified essential features of the changes and continuities within and across cases (Thomson et al., 2003). We used tools of framework matrices, mapping and case memos in NVivo 11.0 to help us better structure the longitudinal data and visualize the changes and continuities of their relationship and experiences over time. The framework matrices and the mapping facilitated a visual overview of the longitudinal data. Time-related concepts emerge during the mapping and we reference back to the matrices when specific examples are needed.

We moved to interpretive level of the analysis by employing Saldaña’s (2013) framing and interpretive questions to help us capture the nature of changes and continuities through thematic analysis. We explored how the changes or continuities have occurred to explain their meanings. Framing questions focus on the contexts and conditions that influence changes over time. Interpretive questions include how changes
relate to one another. Examples questions include the difference from time one of data collection to other times of data collection and what becomes more clear and obvious over time.

Senses Framework is also a useful lens in longitudinal analysis. The changes of their experiences of the senses are subtle but are well connected with and embedded in their experiences, interactions, and relationships. The senses serve as another source of clue for us to follow their navigation in living with cognitive impairment.

The two coders met to discuss and compare the coding decisions and disagreements were resolved in the group. During analysis, memos were kept to clarify coding decisions (Sandelowski, 1995). We referred to the original transcripts when we need more context and information.

4.2.5 Rigor

Multiple strategies were used to establish qualitative rigor (Guba, 1981). For credibility, we engaged other team members so that those who did not participate in first-level coding can review and challenge our interpretations. To further ensure confirmability, we had regular meetings of the group to discuss the definition of codes and coding. The combination of cross-sectional and longitudinal analysis not only helped us understand the meaning of participants’ changing experience and relationships overtime but also made it possible for us to not lose any details of the
dyads’ stories. Rich descriptions of the dyads’ story with the use of quotes of participants permitted comparison of the context in this study to other contexts and made judgement of fitness possible. For dependability, we kept summaries and memos of all the discussion among members of the cross-cultural team to keep track of the process of interpretation. The refinement of the codes and themes were discussed by the first and last author, which facilitated joint decision making on the coding schemes and categorization of coded data.

4.3 Findings

In this study, we explored changes in participants’ dyadic relationships and relationships with others involved in their life through their changing dyadic experience during the time period of extended cognitive decline. They interpreted and reacted to multiple challenges in communication, daily life and care based on their life history, spousal relationships, social networks, current conditions, and access to support and services. PWCI and their care partners tried to maintain the normalcy of their life and relationships by adapting their strategies in collaboration with each other, in face of changing needs and shifting roles. They identified and experienced positive aspects of living with cognitive impairment as they adapted to the changes and coped with challenges. Person-centeredness in daily life and care and pursuit of the six senses in Nolan’s Framework strengthened their positive experiences.
4.3.1 Relationships

Living with cognitive impairment has a great impact on PWCI and their care partners’ dyadic relationship and their relationship with others. The changes in relationships can be associated with the dyads’ perceptions of cognitive impairment, social stigma, increased behavioral symptoms, and care needs. As PWCI grow more dependent on their care partners in daily life, the dyads experience profound changes in their spousal relationships and their relationship with others.

4.3.1.1 Dyadic Relationship

At a milder stage of the cognitive impairment, the dyads start to feel subtle changes in their relationships and their roles in the family. As time goes by and PWCI’s cognitive impairment progresses, managing dementia-related behavioral symptoms makes the dyads feel less of the intimate nature of their spousal relationship both socially and interactively. Instead, it becomes more of an extension of a caregiver-care recipient relationship. However, some dyads were able to make sense of some of the changes after having a deeper understanding of the disease and identify positive aspects in their dyadic experiences so that they can maintain a certain level of continuity in their spousal relationships.

CP2 is the husband of CR2 who was diagnosed with MCI first and now live with mild dementia. CP2 has diabetes and his wife (CR2) has been doing all the housework,
taking care of him and helping him manage his disease for over 20 years. When CR2 was diagnosed with MCI a few years ago, the dyad tried to maintain the normalcy of their relationship and roles in the family. CP2 encouraged CR2 to continue to do housework and run errands as a way of slowing down the progression of her cognitive impairment. CR2 also regarded herself as a caregiver of CP2 and managed his diet, “He has diabetes and I do not let him eat too much sugar. He sometimes cannot help but wants to have chocolates and candies. I would tell him not to do so. I take care of him.” (CR2)

However, as CR2’s cognitive function declined, CP2 experienced increasing negative sense of continuity of their relationship. He still insisted letting his wife do most of the housework although it took longer and more efforts from him because he needed to rearrange and sometimes even re-do what his wife has done. He had a sense of purpose that it is his job to help maintain his wife’s ADL and IADL abilities by creating opportunities for her to engage in activities and housework. However, CR2’s cognition continued to decline, CP2 had to do almost all the housework, which is new and challenging to him. He had to become the leader in the house rather than his wife. Currently, CP2 needs to not only do all the housework but also provide ADL and IADL care for his wife.

“I am very tired. I need to do almost everything on my own, not just the housework but also take care of her. You know what made it harder? She does
not listen to me. We used to have the connection between us. Our family functioned very well. We used to share responsibilities, discuss about things and make decisions together. Now I have no one to discuss with. We don’t have many relatives here. She was the backbone, the leader of the family. She took good care of me and the children but now I need to worry about everything all on my own. I feel lonely and helpless sometimes.”

CP2 experienced a lack of sense of continuity of their relationship and the diminishment of the special connection between them. They tried to maintain the normalcy of their relationship and roles in the family but CP2 is overwhelmed by playing the role of the primary care partner of CR2 especially when he feels that he is fighting on his own.

CP3 and his wife (CR3) formed a step family 20 years ago. They were both widowed at that time and fell in love with each other. They value each other very much because they believed that it is very hard to fall in love with someone at their age. They were very close and took care of each other. During the time when CR3 showed dementia-related behavioral symptoms a few years ago, CP3 and CR3 had some fights,

“We have been married for over 20 years. We rarely had fights but a few year ago, we started to have some fight. Now when I look back, I know it was the disease. But I did not know at that time. I cannot remember the reasons of the fights. I only
remember that she misunderstood me in some situations and blamed me hard. She was a very gentle and smart person. I felt that something went wrong but I was not sure.

Then I went to Australia to visit my daughter. When I returned home, she was different. I took her to the hospital and she was diagnosed with MCI.”

CP3’s perceptions and his way of treating CR3 changed greatly after learning more about the diagnosis. He regarded her as his wife and a patient who needs lots of care and patience from him. He made their photos into video and watched the video with her to remind her of their shared memories. As CR3’s cognitive function declines and physical limitations increase. She has urinary incontinence but refused to use diapers. CP3 decided to respect her choice because he does not want to force her and make her feel uncomfortable. He has been looking for knowledge and information of providing care for PWCI. He respects and loves his wife but he is stuck in the gap between CR3’s care needs and his caregiving capacity.

“She is very dependent on me not only for help in daily activities but also for a sense of security. She feels secured when I am with her. Everyone says that you should let her wear diapers. I said no, she does not like it. I would rather make it harder for me as long as she feels comfortable. I can feel that this enhanced the trust between us even though she did not say anything. I used to watch the videos with her but now I cannot because I have more things to do and more things to worry about now. She needs more
care from me than before. I am too busy to have some quality time with her as husband and wife.”

Both dyads experienced a lack of sense of continuity of their dyadic relationship. There is role shifting, the loss of joint decision makers, and diminishing of connections and special bonds within the cases as the gap between their care capacity and PWCI’s care needs widened and PWCI’s cognitive function declined. Care partners can be overwhelmed by the increasing caregiving burden so that they have to focus more on the caregiver-and-care recipient relationship rather than maintaining intimate and loving spousal relationship in certain circumstances. Nevertheless, their loving spousal relationships and a sense of purpose of providing good care for their loved ones still play important roles in helping them identify positive aspects in the trajectory.

4.3.1.2 Relationship with Others

PWCI experience changes in the relationship with others for multiple reasons. Some PWCI’s friends stop inviting them to social activities in fear of having to take responsibilities for any accident that might occur. Some PWCI decreased their contact with friends and colleagues because they want to hide their conditions from others or that they have increasing challenges in communication. Care partners also experience changes in relationship with others because they need to focus more energy and time on taking care of PWCI.
CP5’s husband (CR5) has an early onset dementia who was diagnosed at the age of 52. It has had great impact on her and her husband’s relationship with others. At first, CR5 decided to hide his condition from others. But as he shows more dementia-related behavioral symptoms, he had to quit his job. His friends and colleagues invited him for dinner party at first and they drank at the party. But then they stopped inviting him after he got lost on his way to one of the dinner parties. CP5 and CR5 have been living in the neighborhood for almost 30 years and they have very good relationship with their neighbors. CR5 wanted to hide his condition from his neighbors as well but CP5 insisted telling them the truth,

“I told him that we need to tell the neighbors. They will understand us. Lots of people have this problem now. See the long waiting line at the memory clinic. They can help me take care of you while I am away running some errands. If you don’t tell them, they will be confused and ask why you are acting weird recently.”

As CR5’s condition declines, he seems to lose his interest in socializing. He tends to use his “brain problem” as an excuse for not going out of the home or talking to others. His withdrawal can be a result of his diminished ability to interpret stimuli and decreased ability to sustain a continuity of focus because of dementia.

“She always asks me to go out with her, to the grocery shop or to have dinner with her friends and family. I am not interested. You see, my brain is not working very
well now. I want to stay at home.”

CP5 is an outgoing person and has many friends and a close relationship with her three sisters. CR5 is not very happy when she goes to hang out with her friends.

“He does not want me to go out. I said why I cannot go out to see my friends. I have done all the housework, I have prepared lunch for you and asked the neighbor to keep an eye on you while I am away. It will only take a couple of hours. I asked you to go with me but you don’t want to. He tells me that he does not want to go nor does he like me going. What can I do? I can do nothing about it. I told him if I stay at home with you all day long, I will be mad at last.”

At the third interview, CP5 told the interviewer that she has managed to play some video games with her friends online at night. She waited her husband fall asleep and then she would stay up late to play cell phone games with her friends so that she can have some time to herself and her friends. She also goes out to play mahjong once a week at night to relax herself.

“My son is very good. He lives with us and goes to work Monday through Friday. But he helps me whenever possible. He is very concerned with my health and told me that why don’t you go out to play mahjong with your friends at night. I can take care of dad. Don’t worry. You cannot just stay at home taking care of dad, it will drive you crazy. I am so moved by my son. He talked to his dad and my husband agreed. My
husband loves his son and always listens to him.”

CP5 also planned a successful little trip for her husband. They travelled with CP5’s sisters and CR5 felt safe surrounded by people he knows and had a good time. CP5 also felt relaxed because her sisters all know CR5’s cognitive impairment and were able to help her a lot during the trip.

As a person with early-onset cognitive impairment and his care partner, the dyad experienced the shrinking of their relationships with others because of the social stigma of cognitive impairment and CR5’s lack of sense of purpose in his life as his dementia-related challenges accumulated. CP5 was placed in a difficult situation by his husband but she actively adopted coping strategies to maintain some of her relationship and engage his husband in some social activities.

As was introduced, CP2 has diabetes and his wife (CR2) has been doing all the housework, taking care of him for over 20 years. CR2 was diagnosed with MCI a few years ago. At first, CR2 went to play taichi everyday and tried to hide her disease and manage others’ perceptions of her condition by bringing some gifts or home-made food to her friends at the taichi class hoping that others will see her as a friendly and normal person. Her husband (CP2) went to tea party in the neighborhood everyday and play chess there with his friends. However, as her cognition declines over time, it is getting harder and harder for her to hide her conditions from others and remember what was
taught and practiced at the taichi class. Eventually she stopped going to the class. CP2 can only go to the tea party once or twice a week by bring CR2 with him as he needs to pay more attention to CR2 and eventually he cannot go to the tea party any more.

“My life is all centered on her. I cannot go to the tea party and play chess. Impossible. I tried to bring her with me to the tea party but she does not enjoy being there. I have to quit my hobby because she is confused and gets lost easily. I need to always keep an eye on her and never leaves her alone at home. I miss my friends but I am unable to go there now. My only outdoor activity each day is to go to a breakfast place and have breakfast with her. I used a leash (for babies) so that she will not walk away from me and get lost at the market.”

Both dyads experienced the shrinking of their relationships with others because of the decline in their cognitive function and other functional abilities, the social stigma of cognitive impairment, and the increasing caregiving burden. Care partners adapted to the changes and experienced a lack of sense of continuity in their relationship with others. Some care partners managed to maintain a certain level of continuity of their relationship with others by actively coping with the changes in life.

4.3.2 Communication

PWCI and their care partners experienced challenges in their communication due to manifestations of cognitive impairment, sensory decline, changes of daily routines,
disparities between limited caregiving capacity and increasing caregiving burden/needs, and other socio-cultural factors. The dyads adapted their communicative patterns in their daily activities and interactions.

CR1’s cognitive function has been relatively stable since he was diagnosed with MCI in 2014. He and his wife CP1 have been taking care of each other in the past 50 years. CP1 did most of the housework and was the primary caregiver of her father-in-law who passed away a couple of years ago at the age of 102. CP1 is the role model of a filial daughter-in-law in the community. Their son and daughter-in-law moved in to live with them after CR1’s father passed away. When CR1 keep having manifestations of cognitive impairment that led to his wife’s lack of sense of security, such as forgot to turn off the stove and left the front door open, his wife could not help but to point out whenever he did something wrong or forgot something, trying to help him remember “what he should remember”. She also corrected CR1’s words or phrases when he is speaking.

“He left the stove on and the water was boiled away. He forgets this and that. Some could cause real danger. I was scared. I pointed it out to him, but he gave me the face that he did not care. He said to me since you found it, why didn’t you just turn the stove off. You don’t need to tell me. How could he say that to me? He also made lots of mistakes in sentences when he is speaking. I corrected
him because I wanted to help him. But he got annoyed. I was just trying to help him.” (CP1)

CR1 told the interviewer that, “It is annoying. I am fine. She does not need to correct me all the time. It feels like she is reminding me that I have a problem with my brain. You can just turn off the stove or close the tap. You don’t need to say these things again and again. It does not help. She also likes to correct me when I am speaking. Very annoying.”

As CR1 has increasing difficulty in speaking, he got more reluctant to talk to others. His wife (CP1) then pushed him to speak to others at home and in the community. This has been resisted strongly by CR1, leading to verbal conflicts. In CP1’s eyes, she must never have direct conflicts or fight with her husband in front of her adult children, especially her daughter-in-law. Thus, their disagreement and conflict developed into sort of a cold war. After struggling for quite a while, CP1 and CR1 gradually changed their way of communication. Instead of blaming him for doing something wrong constantly, CP1 would just correct what he did wrong and then tell him later in a relaxed tone that he forgot something but no worries, she has done it for him. She would sometimes make a little joke when CR1 forgot what he wanted to say and help him when he had difficulty searching the right words to use. She experienced a sense of achievement when she knew exactly the words that her husband was searching.
for. Despite difficulty in speaking and declined hearing, her husband (CR1) communicated with CP1 in his own way. He goes to the community hospital to pick up prescriptions for his wife (CP1). When CP1 broke her leg in 2016, her husband (CR1) tried his best to take care of her. He pushed her wheelchair and took her out for a walk every other day. He held her hands when she tried to move at home. When CP1 is doing the cleaning, laundry or other housework, he (CR1) would stay with her and give a hand when he believes is needed or when being asked to do so.

There are times when CP1 feels helpless, impatient and angry. She would remind herself that it is the disease not her husband. She strengthened her sense of purpose and make sense of her commitment by telling herself that,

“I have not been very well since I was young. I easily get sick. I have diabetes and high blood pressure. He (CR1) helped me and took care of me when I was sick. He also helped me with the treatment of diabetes. Now it is my turn to take good care of him.”

The couple (CR1 and CP1) had a hard time adapting their way of communication to the changes in their life. They also experience a lack of sense of continuity and belonging. However, both of them tried their best to show support and respect to one another. CP1 made sense of her husband’s behavioral symptoms and gain a sense of purpose by reminding herself of the commitment that her husband has made to taking
CR4 was diagnosed with mild dementia at the age of 62. His cognitive decline progressed fast. His wife, CP4, experienced a lack of sense of continuity in her life and her relationship with CR4,

“He used to be a very sweet person. He cares about me a lot. But now, he does not. When I carried heavy bags full of grocery home, he did not come to help. He just sat there without even looking at me. I threw up very badly the other night. He was awake but he just sat on bed doing nothing. Not even bring me a glass of water or ask how I was feeling.”

CP4 was upset about all the changes in their communication and relationships at first but then she gradually adapted her way of communicating with CR4 and her view of their relationships.

“It took me a while to accept that he probably cannot act like what he used to be. I don’t expect that he would care about me like he used to. Instead of getting upset with him and feel sorry for myself, I decided to tell him what I need and what I want him to do. I told him to help me with the heavy bags; and to save some good food for me and our daughter rather than just eating everything on the table….of course it feels different and not as good as before, but it works.”

As CR4’s cognition continues to decline, the couple adjusted their way of care of her in the past decades.
communication and their expectations of life. They gradually developed a verbal and non-verbal communicative system built upon years of shared life experiences, mutual understanding, respect and good observation. The system helped greatly after CR4’s dementia progressed to a moderate level and relocated to a nursing home. It helps CR4 communicate with her husband even though he has difficulty in speaking. It also helps her to tell whether her husband is in pain, in comfort and interpret what he needs. Such experience brought a sense of achievement, significance and belonging to CP4.

“He used his hands to make a shape of square, my daughter was confused but I knew it immediately, he wanted his medicine. I got him the medicine and he was smiling. I know I am right. I always try my best to communicate with him no matter what, and we sort of have a special connection. This is also why I need to be there to care for him. I cannot fully trust others to be able to communicate with him.”

Both dyads have a lack of sense of continuity when they experienced challenges or had difficulty in communication. Care partners’ sense of purpose such as providing the best possible care for their spouses, rewarding their spouses for their commitment in the past years, and slowing down the progression of their cognitive function are the engine that drives them to employ different strategies to improve their communication. It also works the other way around that the establishment of effective communication through their collaborative work helps them maintain or strengthen a sense of purpose.
4.3.3 Daily Activities and Care

All the dyads experienced challenges created by the gap between increasing caregiving burden and limited caregiving capacity. They have a lack of knowledge of the disease, treatment, and care. They have limited access to clinical expertise and quality care service. However, some care partners’ spontaneous thoughts of respecting their spouses’ choices and feelings; meeting their spouses’ personalized needs correspond well with the concepts of person-centered care.

4.3.3.1 Access to Clinical Expertise and Care Service

All the dyads have some challenges or inconvenience of prescribing and filling up prescriptions due to the factors that prescriptions are only available in memory clinics of big tertiary hospitals, limited coverage of the medicines by the insurance, and limited amount of the medicine that they can have each time from the memory clinics. It can take them a whole morning or whole afternoon if adding the time of commute and the time of waiting in the hospital. For those who are the only caregivers of their spouse, they need to either bring their spouse to the hospital or leave them at home alone. Some need to go to the hospital twice a month due to the limited amount of medicine that they can get each time. The dyads have limited or no access to quality care services. There is a gap between their social support system and the caregiving capacity needed.

Some dyads expressed their confusion and uncertainty of the effects of the
medicine or treatment. Although they know that it is incurable, they still have a negative sense of achievement as their spouses’ cognitive impairment progresses fast when they believe that they are providing the best care that they could and adhere to the treatment strictly. It made some of them turn to other source of treatment they can access. CR6 was diagnosed with MCI a few years ago. She and her husband (CP6) believe that her cognitive function is declining faster than expected. They are both highly-educated. They read the medicine instructions carefully and search online for effects and side effects of the medicines prescribed. They believe that CR6’s vomiting is related to the side effects of the prescribed medicine. They consulted the doctor but CP6 still decided to stop the medicine for a while and try some supplements that claim to be able to promote memory and slow down the progression of MCI and dementia. Since then, CP6 has purchased different kinds of supplements and let her wife try them. He took note of his wife’s feeling after taking the supplement and the evaluated the effects. He believes that some of the supplements are helping slow down the progression and alleviate the sides effects of the prescribed medicines. His wife did not believe that the supplements can really work and took the supplements for her husband at first because she thinks that this would give him a sense of purpose and make him happy and fulfilled. However, after a while, his wife starts to believe that these supplements do work and they spend quite an amount of money on purchasing these supplements.
The dyad has a lack of knowledge of the disease and treatment. They have confusion, uncertainty, and unrealistic expectations of the effects of the medicine or treatment. They are very cautious of the medicines prescribed by clinical experts. However, they are open to other sources of medicine/supplements that they can access even though the source is not professional nor reliable.

As was introduced, CP2 experienced increasing negative sense of continuity in the progression of his wife’s (CR2) cognitive decline. As CR2’s cognition declines, CP2 had to do almost all the housework and take care of CR2. He is overwhelmed and has no quality care service to access,

“I wanted to have her at home for as long as I can but I am overwhelmed. See how dirty the room is. I have no time or energy to do the cleaning. Now I am OK with sending her to a center during the day time. I wish there were a good day care center that I can send her to. I went to the one near our community, but it is not good. Now my son comes to visit us every weekend and brings us some food. He is very busy and he has his career and family to take care of. We did not want to be a burden on him.”

Even though CR4 has stayed in a nursing home for over two years. His wife (CP4) is still overwhelmed with taking care of him. CP4 stays in the nursing home with him from 8am to 6pm Monday through Saturday because one nursing aide needs to take care of many residents and service quality is low,
“You cannot count on the nursing aide to provide good care for him. It is impossible, they are too busy and assigned to too many residents. I am sort of a private nursing aide of my husband. I live with my daughter now. I bag the lunch and take a bus to the nursing at 7am. I usually arrive at around 8am and leave at 5:30pm and get home at around 6:30pm. I help him eat breakfast, go to the rehab in the morning if it is prescribed. I massage his legs and talk to him. I will let him eat the home-made lunch because first of all, I can start feeding him earlier and second it is more nutritious. I now have a back pain because I have no place to lie down during the day. I can only sit on a chair to take a nap. My daughter comes to take care of him on Sunday and I do grocery shopping and housework on that day. I cannot remember what was the last time that I had a good day rest.”

The dyads have a lack of access to clinical expertise and quality care services in the home and community-based settings and formal LTC settings. It posed increasingly greater challenges to them as PWCI’s cognitive functions decline and grow more dependent on their care partners.

4.3.3.2 Caregiving Concept Related to Person-centered Care

All the care partners in this study admits that they have a lack of knowledge and skills in providing care for PWCI and would like to have more access to training in
different forms and opportunities to communicate with other care partners. There is a gap between their caregiving burden and caregiving capacity. The gap challenges them in their daily life, but their desire of seeking for knowledge and spontaneous thoughts of respecting their spouses’ choices and feelings; meeting their spouses’ personalized needs correspond well with the concepts of person-centered care.

CP3 and his wife (CR3) formed a step family 20 years ago. CR3 showed dementia-related behavioral symptoms a few years ago. Her cognitive function declines and physical limitations increase. She has urinary incontinence but refuses to use diapers. Her husband respected her choice because he does not want to force her and make her feel uncomfortable. After CR3 wetting the bed several times, CP3 has to get up in the middle of the night and ask her to use the bathroom. He helps her sit on the toilet and get up to avoid fall accidents. This has affected his sleep quality negatively. He has been looking for knowledge and information of providing care for PWCI. Although there is almost no availability of books in Chinese that are both informative and user-friendly on this specific topic, he does have some general concepts in providing care based on his beliefs, values and their relationship in marriage,

“You need to respect her choice as much as possible. She does not want to use diapers. I tried to explain it to her but she still refuses to use it. I guess she does not like the feeling or the diapers confuse her. That is my rule, I communicate with her first to
understand her needs and preferences before I make decisions on her diet and daily activities. I always tell her it is you who is helping me and yourself. I am just assisting and guiding you to help yourself. For example, when I try to move her, I cannot just force it, I need to have her cooperate with me and we work together on it. Otherwise, we might both get hurt. This is just some of my thoughts but I have lots of questions about how to take care of her and myself. For example, she is not eating well and you can see she has lost some of weight since last year. I know nutrition is very important and I am very concerned but I don’t know how to help her in reality.”

When CP4 was feeding her husband (CR4) one day, she used a cloth to tie his arm so that he would not knock the bowls over to the floor by accident. She made sure that it was not tight and would not make him feel uncomfortable. However, she forgot to untie his arm before she went to wash the dishes. After she returned from the kitchen, CR4 was crying hard in the room. CP4 was shocked and had a deep sense of guilty.

“I have never seen him crying like that before. He was crying like a child. I was shocked and blamed myself so hard that I hated myself at that time. How could I do that to him. I made a bad decision. I started to question myself if I made other bad decisions when taking care of him. It is very hard.”

In their daily activities and care, all of them experienced a lack of sense of continuity. Some of the dyads have to adapt to their new roles at home. Some PWCI
struggle to accept that they need to live with cognitive impairment in the rest of their life and are unable to do things that they used to be good at. Some care partners have a strong sense of purpose of making their spouses’ cognitive function stable and slow down the progression. The progression of their spouses’ cognitive impairment affects some care partners’ sense of achievement, making them think that they are not providing care that is good enough to slow down the progression. As time goes by, some dyads managed to regain a sense of continuity and achievement despite new challenges that keep coming up in their daily life.

4.4 Discussion

The current study explored PWCI and their spouses’ dyadic experiences of living with cognitive impairment and their relationships over time, through a person-centered care lens. The themes that are identified and connected across time points illustrate the complexity of the dyads’ changing experiences.

Previous research has emphasized the importance of the relationship between PWCI and their care partners to dyadic well-being (Ryan et al., 2003; Braun et al., 2009). This is consistent with what we found from our study, in that PWCI and their spousal care partners’ perceptions of changing relationships and well-being with each other directly affected their experience of living with cognitive impairment over time. The spouses were first involved in the process of making sense of the changes in their life
and then attempted to adapt to the changes independently and jointly. As the balance of the relationship changed, PWCI and their care partners adapted their strategies to cope with the changes. Both problem-focused coping and emotion-focused coping were identified in their narratives (Quinn, Clare, Pearce, & Dijkhuizen, 2008). They managed the situation by developing practical methods of dealing with their declined cognition. They also used emotion-focused coping such as making sense of the situation and finding and strengthening their sense of purpose of care provision. Our findings indicate that it is crucial to help PWCI and their care partners choose a more positive attitude and nurture the belief that there is significant meaning in the journey of living with cognitive impairment.

PWCI and their care partners’ relationship is not merely caregiving and receiving or an extension to care relationships. Our findings suggest the importance of recognizing the nature of their relationship in developing and implementing care programs. To employ a person-centered approach, providers must take into account a person’s significant relationships. When care partners and PWCI experience well-being through the Six Senses (Nolan, 2004), their relationship is more interdependent and reciprocal, whereby spouses were care partners who worked with them, instead of worked for them to adapt to the changes in life as a couple.

Care of PWCI is individual-focused but also family-oriented. The key connection
is the relationship between PWCI and their primary care partners. The responsibility of providing care for one another is viewed as essential nature of spousal relationship (Russell, 2001). Although caregiving has been traditionally described as a feminine activity, men are taking important roles as care partners for their wives with cognitive impairment (Baker & Robertson, 2008). Our findings indicate that husbands can be capable care partners providing quality care and have their strengths and weaknesses in caregiving. The progressive nature of cognitive impairment and the changing needs from PWCI can bring a sense of uncertainty and unpredictability to care partners. The long-lasting and preset family roles shift through the process (Au et al., 2013). The couple have new experiences and face the adaptive challenges of learning new skills, building new connections with each other, and changing their beliefs and behaviors, including their gender role perceptions. For those who have been dependent on their wives to do most of the housework, they may be overwhelmed by learning and completing housework and perform instrumental tasks associated with ADL/IADL care. They might be too overwhelmed to make enough emotional commitment to PWCI. For wives, the previous emotional work and housework may have continued, but they may experience more discontinuities in their roles as they have to assume more authority in decision making within the family (Arbel et al., 2019). However, our findings also show that we need to be careful in interpreting gender roles and expectations in caregiving
because there are differences at individual and family level. We need keep in mind the heterogeneity when we design interventions to support the spouses in the journey of living with cognitive impairment. The higher rate of employment among females, the more equal share of housework between husbands and wives, the changes of life routines and roles at a later stage of life after retirement, and different individual personalities and family dynamics can all affect the couples’ interpretation of their challenges and the coping strategies (Sharma, Chakrabarti, & Grover, 2016). In terms of homogeneity, both men and women experience a lack of achievement when they feel that their work is not valued by others. Their strong sense of purpose is rooted in the belief of proving the best possible care for their loved ones and have them age in place.

Our findings also suggest the importance of optimizing opportunities for PWCI to be engaged in meaningful social relationships and support. Informal support is a valuable resource and is particularly important when formal support and services are lacking. Our findings suggest that there exist significant opportunities to increase awareness and reduce stigma of cognitive impairment, to facilitate PWCI and their care partners’ connections with external sources of support or help. Prior research has demonstrated the benefits for PWCI and caregivers alike from access to peer support group (Chien et al. 2011). For example, sharing experiences and stories within the group can be therapeutic and help them reflect on their own life (Chien et al. 2011). Our
findings highlight some of the important barriers related to lack of availability and lack of knowledge of such services, as well as stigma of the disease, that may be preventing community-based families from accessing support (Chien et al., 2011).

We found in our study that working together to have effective communication is an effective strategy to manage changes in their life and relationships. The earlier PWCI and their care partners start, the better their communication will be at a later stage of dementia (Clare & Shakespeare, 2004; Hellstrom et al., 2005; Keady, 1999; Keady & Nolan, 2003). As the illness progresses, the spousal care partners’ experience of separateness and responsibility increases. PWCI hands over their responsibility to their care partners. This is especially true when PWCI used to take more responsibility of housework and there is a reverse of their roles in the family. If the shift happened quickly without preparing the care partners or providing enough support needed, it might negatively affect care partners’ well-being. Our findings indicated that PWCI could play an active role in transferring their knowledge and skills to their partners while they are still able to do so through collaborative work with their care partners, which is a key concept in adaptive leadership framework (Corazzini et al., 2014). This is an important implication for practices in different care settings that formal caregivers and providers can intervene at the early stage to assist in the collaborative work between PWCI and care partners in knowledge, skill and role transferring.
We found in our study that the lack of knowledge of the disease, treatment, and caregiving can potentially negatively affect PWCI and their care partners’ coping and overall well-being throughout the process of living with cognitive impairment. Care partners repeatedly expressed frustration at not being able to figure out how to assist their loved one. Others engaged in costly treatments with no scientific validity or had care interactions that exacerbated mutual distress. By contrast, our findings also provided many examples of when care partners respected PWCI’s choices, regarding caregiving as assisting and guiding PWCI to help themselves instead of telling them what to do, resulting in a profound positive impact on the well-being of PWCI and their care partners and most importantly, on their spousal relationships. These latter examples support Edvardsson et al.’s, (2010) findings related to the mutually beneficial effects of person-centered dementia care.

The quality of spousal relationship between PWCI and their care partners is viewed as a central dimension of the overall experiences of care, particularly, the positive aspects of caregiving (Carbonneau et al., 2010). Our findings align with the conclusion and also suggest that person-centered concepts embedded in the provision of care can facilitate the experiences of positive aspects of caregiving and improve spousal relationships. In our study, some care partners make sense of the changes and adapt to their roles more smoothly than others because they interpreted and experienced more
positive aspects in the provision of care, such as the significant meaning of care, gains from care, personal growth, improved relationships and higher self-esteem (Lloyd et al., 2016). PWCI and their care partners are likely to experience raising level of hopelessness and helplessness due to the progressive nature of cognitive impairment. These negative senses may affect their well-being and increase the appraisal of caregiving burdens. It is crucial for health care team members to understand PWCI and their care partners’ roles in the journey, enhance positive activities in their daily life, help them achieve personal growth, discover their strength, promote personal connections with each other, and gain a sense of purpose along the journey. The act and the acknowledgement of their giving and commitment are identified by Nolan et al. (1994) as a core domain of positive aspects of caregiving and satisfaction, which can lead to senses of purpose and achievement. I also found that the collaborative work carried out by PWCI and their care partners are the key to adapting to changes in the journey and improving their reciprocal partnerships through experiences of positive aspects.

Our findings regarding the cultural relevance of person-centered care is consistent with the current evidence that traditional values can be a facilitator and barriers for implementing person-centered dementia care (Chan, 2010; Xiao et al., 2014; Mahoney, Cloutterbuck, Neary, & Zhan, 2005). Treating others with dignity and respect, as a core concept of Confucius philosophy (Chan, 2010), can serve as a facilitator of
implementing PCC in China. Some other notions in Chinese culture can be regarded as barriers to person-centered dementia care, such as the perceptions of patient-hood (Kong et al., 2017). Our findings indicate that the idea of maintaining relational or family harmony by avoiding direct conflict can be a double-edged sword and had mixed effects in different stages of their cognitive impairment. As we found, it can help increase couples’ tolerance for each other and maintain family harmony. However, we also found that the hiding and avoidance of direct confrontation can hinder their honest and timely communication and increase the tension between the dyads and within the family when the gap between care partners’ caregiving capacity and PWCI’s increasing needs widens. It also applies to the acceptance of cognitive impairment as a destiny in life. This cultural belief may help them accept the diagnosis as a fate and protect them from a sense of guilty at the beginning, but as they navigate in the extended period of cognitive impairment, this belief might prevent them from seeking for more knowledge and skills of caregiving, reaching out for help, and conducting adaptive work to deal with the challenges (Mahoney et al., 2005). Our findings also show the importance of having scientific understanding of cognitive impairment. After having a knowledge of what cognitive impairment is from the clinical expertise, the care partners made better sense of PWCI’s behaviors and proactively reached out for support within and beyond the community. Thus, an awareness of this nuanced cultural context, would strengthen
efforts to develop person-centered interventions for PWCI and their care partners. I also find in my dissertation that we need to be cautious when we interpret perceptions, attitudes and values from one culture, as seen in the diversity of each couple’s experiences. It is important to recognize the important differences in cultural context among individuals, families, and communities.

There are several limitations to this study. First, the current study used fixed times to conduct follow-up interviews with the participants from 2015 to 2017 for pragmatic reasons, rather than time follow-up in response to significant events. Nevertheless, we successfully captured changes in cognitive function, coping strategies, experiences, and relationships over time. Second, the participants in our study all lived in a big city of China, which may differ significantly from the experiences of those who lived in underdeveloped areas in China. Given other research of the health disparities between urban and rural areas in China (Wu, Yue, & Mao, 2015), the comparison would be an area for future research. Finally, other family members such as adult children are not included in the current study, and thus we did not have external perspectives on the dyadic spousal relationship.

4.5 Conclusions

The complexity of PWCI and their care partners’ changing experience of living with cognitive impairment is interpreted in the context of the dynamic nature of their
spousal relationship and relationship with others, patterns of communication, daily activities and care during the extended period of cognitive decline. PWCI and their care partners used strategies to adapt to the changes and cope with challenges. The dyads experienced a lack of sense of continuity of their relationships, communication patterns, and daily life and activities. Some care partners managed to maintain a certain level of continuity of their relationship and life by actively coping with the changes in life. Care partners’ sense of purpose such as providing the best possible care for their spouses and slowing down the progression of their cognitive function is the engine that drives them to employ different strategies to enhance their communication with PWCI and seek for knowledge of caregiving. PWCI and their care partners have a lack of access to clinical expertise and quality care services in the home and community-based settings and formal LTC settings. It posed increasingly greater challenges to them as PWCI’s cognitive functions decline and grow more dependent on their care partners. It is acknowledged that PWCI deserves opportunities to be engaged in meaningful social relationships with others. It is crucial to help PWCI and their care partners choose a more positive attitude and nurturing the belief that there is a significant meaning in the journey of living with cognitive impairment. Quality care services for PWCI should employ a relationship-centered approach that takes a person’s significant relationships into consideration. Building an effective communicative system at the milder stage of
dementia between the PWCI and his/her care partners will make it possible for care partners to provide PCC at a later stage of dementia.

5. Conclusions

5.1 Summary

We found in our bilingual systematic review that traditional values can be a facilitator for implementing person-centered dementia care, such as the concept of treating others with dignity. Some other notions in Chinese culture can be regarded as barriers to person-centered dementia care, such as the perceptions of patient-hood (Kong et al., 2017). Other concepts, such as the idea of maintaining relational or family harmony by avoiding direct conflict can be a double-edged sword and had mixed effects in different stages of their cognitive impairment. It can help increase their tolerance and maintain family harmony but on the other hand, the hiding and avoidance of direct confrontation can hinder their honest and timely communication and increase the tension between the dyads and within the family when the gap between care partners’ caregiving capacity and PWCI’s increasing needs widens. The model of person-centered dementia care in China that we developed provides a starting point for us to understand and translate core concepts of PCC into a specific socio-cultural context. What we found in chapter 3 is consistent with the findings in chapter 2 that when PWCI receive too much care from their care partners or being told to do what they need to do
by their care partners, they would report feeling less empowered or having a lack of control over their life. This behavior can emerge from the concept of patient-hood in Chinese culture that patients are weak, dependent, and vulnerable, and that their close family should take good care of them and arrange their daily activities to conserve the patients’ energy (Kong et al., 2017). It can be a potential cultural barrier to treating PWCI as competent persons who deserve the right to engage in social activities and decision-making.

In Chapter 3, we explored PWCI and their spouses’ dyadic experiences of living with cognitive impairment through a person-centered care lens operationalized by the Senses Framework (Nolan et al., 2004). Findings indicate that high quality care emerges from the quality of their dyadic relationship and social relationships. We identified the importance of the bidirectional relationship of caregiving. Their dyadic relationship is interdependent and reciprocal that care partners develop a partnership with PWCI and work with PWCI, instead of working for them to adapt to the challenges in life as a couple.

Person-centered care processes are a means of establishing and nurturing the healthy relationships between PWCI and their care partners (Nolan, 2004). Our findings suggest that supporting a PWCI’s personhood in an authentic relationship requires focusing on the interactions rather than on the symptoms or caring tasks. Care partners’
good attitudes and use of supportive verbal and nonverbal symbols can be perceived as caring and may be more important than the actual care received. It makes them feel secure and obtain a sense of belonging. In our study, PWCI and their spouses experienced a sense of achievement when their efforts were well acknowledged through verbal or non-verbal communication. On the other hand, their experience of well-being was threatened when they failed to communicate their feelings with each other.

In chapter 4, we explored PWCI and their spouses’ dyadic experiences of living with cognitive impairment and their relationships through a person-centered care lens in a longitudinal way. PWCI and their spousal care partners’ perceived changing relationships and well-being interplay with each other through their experience of living with cognitive impairment. The spouses were first involved in a process of attempting to understand and make sense of the changes in their life and then adapt to the changes jointly and independently. They developed specific practical methods to address challenges in daily life. They also employed emotion-focused coping strategies such as making sense of the situation and finding and strengthening their sense of purpose. It is crucial to help PWCI and their care partners choose a more positive attitude and nurture the belief that there is a significant meaning in the journey of living with cognitive impairment.
PWCI and their care partners experienced discontinuities in their relationships, communication patterns, and daily life and activities. Some care partners managed to maintain a certain level of continuity of their relationship and life by actively coping with the changes in life. Care partners’ sense of purpose such as providing the best possible care for their spouses and slowing down the progression of their cognitive impairment is the engine that drives them to employ different strategies to enhance their communication with PWCI and seek for knowledge of caregiving.

Across the chapters, we found that PWCI and their care partners can thrive in a person-centered and supportive environment where choice and autonomy are maximized and relationships are nurtured. For PWCI, they have the need to maintain their sense of personhood and normalcy of their life as much as possible at all stages of cognitive impairment in collaboration with their care partners and other people involved in their care and daily activities. From the perspectives of care partners, applying PCC is to integrate person-centeredness in their daily life and activities in partnership with PWCI. Within the person-centered community, PWCI’s personhood and needs are recognized, valued, and translated and their care partners’ well-being is also valued. For formal care providers in the community-based setting, it is important for them to establish a collaborative relationship with PWCI and their care partners to ensure that the decision-making process and care delivery are person-centered,
incorporating PWCI’s and their care partners’ needs, preferences and values with care providers’ expertise.

Collaborative work (adaptive challenges)

Both problem-focused coping and emotion-focused coping were identified in their narratives (Quinn, Clare, Pearce, & Dijkhuizen, 2008). They managed the situation by developing practical methods of dealing with their declined cognition. They also used emotion-focused coping such as making sense of the situation and finding and strengthening their sense of purpose of care provision. Our findings indicate that it is crucial to help PWCI and their care partners choose a more positive attitude and nurture the belief that there is significant meaning in the journey of living with cognitive impairment.

Our findings also suggest the importance of optimizing opportunities for PWCI to be engaged in meaningful social relationships and support.

Our findings indicated that PWCI could play an active role in transferring their knowledge and skills to their partners while they are still able to do so through collaborative work with their care partners.

Others engaged in costly treatments with no scientific validity or had care interactions that exacerbated mutual distress. By contrast, our findings also provided many examples of when care partners respected PWCI’s choices, regarding caregiving
as assisting and guiding PWCI to help themselves instead of telling them what to do, resulting in a profound positive impact on the well-being of PWCI and their care partners and most importantly, on their spousal relationships. These latter examples support Edvardsson et al.’s, (2010) findings related to the mutually beneficial effects of person-centered dementia care.

5.2 Implications for Nursing Practice

Findings from the study indicate that we need to make commitment to increase awareness and openness towards cognitive impairment and facilitate PWCI and their care partners’ motivations of reaching out for help. Community-based quality care services and support led by health care team members, such as psychologists, social workers, and nurses are much needed by PWCI and their care partners. Our findings support the importance of developing services consistent with person-centered care that takes PWCI and their care partners’ significant personal and social relationships into account and acknowledge that they all deserve opportunities to be engaged in meaningful social interactions and relationships. Our findings also suggest that health care team members adopt a proactive, person-centered, and sustainable approach to assess both PWCI and their care partners’ needs and values. Ultimately, this involves not only collaborating with them to facilitate addressing technical challenges, but also to support addressing adaptive challenges, which are challenges that are difficult to define,
have no current or known solutions, require creating new solutions, and often involve changing behaviors and shifting norms or values (Corazzini et al., 2014).

Acknowledging the strengths of PWCI is beneficial for the continuity of their personhood. Acknowledgements from PWCI on their care partners’ commitment is crucial to enhance care partners’ psychological well-being and a sense of achievement. These are important to nurture their spousal relationships and valued partnerships. PWCI and their care partners need to be guided to a more positive attitude and belief that there is significant meaning in the journey of living with cognitive impairment. Health care team members can help by reinforcing positive personal and family attributes that maximize their pleasure. This may help promote their sense of security within the uncertainty throughout the journey. Maximizing the supportive resources for PWCI and their care partners particularly at times of diagnosis and transitions and prepare them for the changes and challenges are the key to improving their well-being.

Findings also suggest that early and continuous interventions and support are important to prepare PWCI to play a proactive role in transferring their knowledge and skills to their partners, planning and making decisions for the future while they are still able to. My findings show that it is crucial to build an effective communicative system at the milder stage of cognitive impairment in gaining cooperation and facilitating partnerships between PWCI and their care partners, so that it will be easier for care
partners to provide PCC at a later stage. Through interventions that engage both PWCI and their family care partners, health care team members ought to help family care partners gradually adopt the role as adaptive leaders who can establish a reasonable and shared goal of communication, adapt the goals collaboratively to the changes in needs and abilities, tailor communication techniques for PWCI, such as threat-reduction techniques, switch from telling to working with PWCI to adapt to new routines in life, and allow PWCI to move at their own pace, (Corazzini et al, 2014; Anderson et al., 2019). PWCI and their care partners ought to have better access to the knowledge of the disease and opportunities to consult with clinical experts or preferred professionals about treatment, decisions making, prognosis, and management of symptoms.

Access to health care team member facilitated and person-centered peer support groups in a combination of modes of delivery, including traditional face-to-face meetings and technology-based smartphone and other mobile devices platforms, can provide PWCI and their care partners with opportunities to share their feelings with and offer emotional support and information for one another, and in turn, create meaningful peer connection and reduce distress. The combination of modes of delivery can overcome some of the limitations in timeliness and locations through traditional in-person meetings and seminars. Health care team members involved can provide sustainable and person-centered knowledge of caregiving and self-management so that
they can build a collaborative relationship with the dyads and support them through their journey of living with cognitive impairment. They can also identify and react to potential ethical problems and crises. Their facilitation can make the consultation, information, and support more evidence-based and professional (McColl, Rideout, Parmar, & Abba-Aji, 2014). Health care team members facilitated peer support targeting both PWCI and their care partners with a focus on the dynamics of their relationships enhances the person-centeredness in the process, and in turn, will increase the dyads’ positive action and creative problem solving in the management and coping of living with cognitive impairment (Zachos et al., 2013). The use of technology can also support the maintaining of PWCI and their care partners’ social networks despite their limited ability to leave the house or time to spend in networking. The needs of PWCI and their care partners change along the progress of the symptoms. Lorenz et al. (2019) pointed out that, in comparison to persons with advanced dementia, most mobile device-based interventions targeting PWCI and their care partners aims to maintain and support PWCI’s memory and cognitive function. However, my findings show that persons with MCI and mild dementia and their care partners do need support in social interaction and networking and the support in enhancing coordination with each other and with other people involved in the care, which is currently lacking.
5.3 Implications for future studies

One qualitative study adopted a longitudinal design to examine the influence of the diagnosis of dementia by comparing couples’ narratives at 2 weeks and at 12 weeks after the diagnosis (Vernooij-Dassen et al., 2006). This dissertation is among the first to draw upon comprehensive longitudinal data of PWCI and their family care partners to understand PWCI’s and their care partners’ experiences of living with cognitive impairment and its long-term impact on their relationships. It serves as a first step towards developing a long-term and person-centered intervention to support PWCI and their care partners through their journey of living with cognitive impairment, through a person-centered care lens.

It serves as a first step towards developing sustainable and person-centered participatory interventions at a couple level to support PWCI and their care partners through their interactive journey of living with cognitive impairment. The interventions can focus on helping PWCI and their care partners to establish effective communication, improve dyadic relationships, and guide them to supportive resources in a person-centered and culturally-sensitive manner. To support intervention development, next steps studies should continue the follow-up interviews and include mixed-methods approaches to integrate empirical qualitative knowledge of changing needs, relationships and caregiving, with quantitative data of trajectories of health and well-
being, over time, to have a deeper understanding of how to support the couples in a person-centered manner to thrive in the journey.

Although the generalization of the dissertation findings is limited due to the nature of the study design, the in-depth exploration and understanding of the dyadic experiences of living with cognitive impairment over time through a person-centered care lens does have some implications within and beyond China in dealing with challenges of dementia care in the home and community-based settings. PWCI and their care partners are likely to experience raising level of hopelessness and helplessness due to the progressive nature of cognitive impairment. These negative senses may affect their well-being and increase the appraisal of caregiving burdens. Person-centered concepts embedded in the provision of care can facilitate the experiences of positive aspects of caregiving and improve spousal relationships. It is crucial for health care team members to support their collaborative work, increase positive activities in their daily life, help them achieve personal growth, and promote personal connections with each other, using person-centered and culturally-sensitive approaches. Helping everyone, not just PWCI and their care partners to have a better knowledge of what cognitive impairment is and reduce the stigma attached to it are significant goals to be achieved around the world. We also need to keep in mind the heterogeneity when we design interventions to support the spouses in the journey of living with cognitive impairment.
impairment regarding their gendered roles and cultural beliefs. Ultimately, our study supported the important differences among individuals, families, and communities in effects of culture on the experience of neurocognitive disorders and resultant roles in the family or as a couple.
Appendix A

Qualitative Questions at Baseline

Older adults:

1. **Grand tour question: Could you please tell me about a typical day of your daily life?**
   - Think about (example from quantitative results). What is easy? What is difficult?
   - Can you give me an example?
   - As you mentioned that xx is easy for you, tell me more. How about: What makes you feel easy? (Someone helps? Some facilities, tools, or coping strategies that if helpful?)
   - As you mentioned that xx is difficult for you, what makes you feel difficult? Could you be more specific?

2. **Tell me about a time when your care partner helped you with things you do each day, such as eating or dressing (or example from quantitative results)?**
   Probes:
   - Think about (example from quantitative results). Tell me about any similar experiences that you have when you were helped with it.
   - If older adults indicate getting help, ask if they wanted help with that activity.
   - If older adults indicate not getting any help with the above domains, ask about IADL (eg. Taking medicine, combing, brushing teeth, cutting toenails and making phone calls.)
   - Could you please give a specific example how he/she helped you?
   - Is it helpful? When happened then? If not, what do you wish he/she would do differently?
   - How did you feel when he/she was helping you? (Some people are happy/satisfied about it, some people not so, what is your experience?)
   - How would you describe the amount of help he/she provides? (Enough or you need more)
3. **Tell me about a time when you wanted help from your care partner but it was not available.**

   Probes:

   - Think about (example from quantitative results). Did you have similar experiences when you wanted help from staff or family members but it was not available?
   - Could you please give a specific example about such situation?
   - Tell me more. How did that happen?
   - Why was it unavailable? (No time, lack of training, unwilling to do so. etc)
   - How did you feel then?
   - In that situation, what did you do?
   - Is there someone that you would like to talk to about this situation? Who is he/she?
   - In that situation, whom do you want to turn for help first?
   - How would you like them to help you (In what ways do you think the caregiver could improve his/her way of caring?)

4. **Tell me how do you feel about being cared by XX (caregiver’s name)? (optional one, skip if the participants answered in the previous questions)**

   Probes:

   - As you mentioned earlier (from quantitative results) that XX (caregiver’s name) is providing care for you, how did she/he assist you in your daily life?
   - What do you like while being cared by (the names of Caregiver)?
   - What makes you feel difficult or uncomfortable while being cared by (the names of Caregiver)?

   **Caregiver:**

1. **Could you please describe a typical day at xx’s home taking of your xx?**

   - Think about (example from quantitative results). What is difficult?
   - Can you give me an example?
   - As you mentioned that xx is easy for you, why do you think it is easy? (Someone helps? Some facilities, tools, or coping strategies that if helpful? )
• As you mentioned that xx is difficult for you, what makes you feel difficult? Could you be more specific?

2. Tell me a time when you got help to care for _____?
   Probes:
   • Think about … (Financial resources, family member support, social network, religious beliefs, and quantitative results) what kind of help are you getting to care for _____?
   • Could you please give a specific example?
   • How did you think of that help at that time? Is it helpful or not? What happened then?
   • If it is not helpful, what would you wish to change?
   • How did you feel in that situation?
   • Do you feel that you need extra help? If so, what do you think might be helpful?

3. Tell me a time when you wanted help to care for _____, but it was not available?
   Probes:
   • Think about (Financial resources, family member support, social network, religious beliefs, and results from quantitative questionnaire) Do you have similar experiences when you wanted help from your care partner but it was not available?
   • What services could have helped you with caregiving, but was not available?
   • Could you please give a specific example about such situation?
   • Why was it unavailable? (No time, lack of training, unwilling to do so, etc.)
   • How did you feel then?
   • Is there someone that you would like to talk to about this situation? Who is he/she?
   • In that situation, what did you do?
   • In that situation, whom did you want to turn for help first?
   • How would you like them to help you (in which way, any other tools or strategies?)

4. Tell me how do you feel about caring for___? (Optional)
   Probes:
• Some people feel stressful taking care of older adults, some people don’t. How do you feel?
• yourself/communicate your emotions? Could you give us an example?
• What has been the impact of caring for _____ on your life?
• What are the challenges you face in performing your daily tasks?
• What are the rewards, and what you dislike about? Could you please say more about it?

5. **You mentioned XX in our previous questionnaire, tell me about how you interact with and support each other.**
   Probes:

   • What makes you think XX (the person in the circle) is important to you?
   • Some caregivers experienced conflicts between caring for XX and caring for yourself/your child/your friend/your family, some did not, what was your experience?
   • How has (the person in the circle) helped/supported you with caregiving? Please tell me about the last time you asked him/her for help with a problem?
Figure 4. Flow chart of Case 1
Figure 5. Flow chart of Case 2
Figure 6. Flow chart of Case 3
Figure 7. Flow chart of Case 4
Figure 8. Flow chart of Case 5
Figure 9. Relationships of Case 1
Figure 10. Relationships of Case 5
References


Smith, M., & Buckwalter, K. (2005). Behaviors associated with dementia: Whether resisting care or exhibiting apathy, an older adult with dementia is attempting communication. Nurses and other caregivers must learn to ‘hear’this language. AJN The American Journal of Nursing, 105(7), 40-52.


Whitlatch, C. J., & Orsulic-Jeras, S. (2018). Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. The Gerontologist, 58(suppl_1), S58-S73.


Biography

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Wang J, Yang, Q., Wu, B. Effects of Care Arrangement on the Age of Institutionalization Among Community-dwelling Chinese Older Adults (In press). *Journal of Aging & Social Policy*


Facilitators and Barriers to Exercise Influenced by Traditional Chinese Culture: A Qualitative Study of Chinese Patients Undergoing Hemodialysis. *Journal of Transcultural Nursing*. [https://doi.org/10.1177/1043659618823908](https://doi.org/10.1177/1043659618823908)


