

Resident Challenges with Functional Limitations and Pain in Chinese Residential Care Facilities

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Dissertation submitted in partial fulfillment of  
the requirements for the degree of Doctor  
of Philosophy in the Department of  
Nursing in the Graduate School  
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ABSTRACT

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## **Abstract**

**Problem:** The demand for residential care facilities is high and still increasing in China. However, the quality of care in these facilities is concerning due to lack of quality control and regulations and insufficient funding. To achieve high-quality care in these facilities, knowledge is needed about residents' care needs and current efforts to address residents' care needs in these facilities. Studies from other countries have reported the high prevalence of functional limitations and pain among residents in residential care facilities. This suggested that residents' care needs relating to functional limitations and pain are potentially substantial in residential care facilities. Therefore, this dissertation aimed to: (1) synthesize existing literature on residents' care needs and current care, and (2) describe residents' care needs related to functional limitations and pain.

**Methods:** Chapter 2 describes a systematic literature review that synthesized evidence on resident characteristics and care needs and staff characteristics and care, and defines areas where research is needed. Chapter 3 describes a qualitative exploratory study that described residents' challenges with daily life in Chinese residential care facilities. Chapter 4 describes a mixed-method, observational study that explored residents' descriptions of challenges with pain and functional limitations.

**Results:** The systematic review revealed that frontline workers received little systematic training for resident care. Chinese residential care facilities had few qualification standards for staff preparation for their roles in these facilities. Also, chronic conditions were prevalent among residents in Chinese residential care facilities. The two observational studies provided three major findings: (1) residents reported significant care needs with functional limitations and pain; (2) residents adopted a substantial number of self-management strategies to address these care needs;

(3) residents faced significant barriers when adopting these self-management strategies, including inaccessibility of health care, unsupportive facility policies and administrators, and lacking staff care.

Summary: Knowledge from this dissertation enhances understanding of residents' care needs with physical limitations and pain in Chinese residential care facilities. This knowledge informs changes to achieve high-quality care in these facilities. This dissertation provides important implications for practice and policy, including: (1) building a resident assessment system with valid tools to comprehensively capture residents' care needs with functional limitations and pain; (2) incorporating into staff training programs knowledge and skills about how to manage functional limitations and pain; (3) developing facility policies to support residents' self-management and frontline workers' strategies; (4) integrating health care into residential care facilities; (5) modifying physical environment to be resident-centered.

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## **1. Dissertation Introduction**

### ***1.1 Residential Care Facilities in China***

The demand for formal long-term care in China is surging (Wu, Carter, Goins, & Cheng, 2005) and still growing due to a rapidly aging population. By 2050, the number of people aged 60 years and older is expected to reach 450 million, or 33% of China's total population (Wong & Leung, 2012), fueling the increasing demand for long-term care services (Zhan, 2013). However, increasing migration from rural to urban areas among young people and the shrinking family size due to China's one-child policy have overwhelmed the traditional, informal family-based caregiving model (Wong & Leung, 2012; Zhan, 2013). To respond to the high demand for formal long-term care in China, the Chinese government has been developing both community services and residential care facilities in the past two decades (Shum, Lou, He, Chen, & Wang, 2015). While a majority of older adults obtain long-term care in the community, the number of beds of residential care facilities has been increasing in the last decade (Ministry of Civil Affairs of the People's Republic of China, 2016a). The institutionalization rate into these facilities increased from 0.5% to 0.8% between the interval of 2002-2005 and 2008-2011 (Peng & Wu, 2015).

Residential care facilities in China provide care mainly for people who are 60 years and older. These facilities in China fall in two broad types of ownership: government-owned and privately owned (Zhan, Luo, & Chen, 2012). Historically, residential care facilities in China were social welfare facilities that admitted only *three nos* or *wubao* (terms referring to people who have no income, no families, and no ability to work). It was not until the 1990s that social welfare facilities became available to older adults not designated as *three nos*. Then privately owned residential care facilities were encouraged by the Chinese government. The past decade saw the

fastest growth in the number of residential care facilities, mainly in urban areas (Wong & Leung, 2012). Of the residential care facilities, government-owned ones have mostly evolved from social welfare facilities that historically admitted only *three nos* or *wubao*, but now also admit self-paying residents. The Chinese government pays for the facility stay of *three nos* and *wubao* residents (Leung, 2006; Wu, Mao, & Zhong, 2009). Privately owned ones are a more recent development and admit mainly self-paying residents (Wong & Leung, 2012). A study in two large cities (Tianjin and Nanjing) showed that government-owned and privately owned facilities differ in many aspects, including resident characteristics (levels of physical function and ratio of self-paying versus *three nos* or *wubao* residents), direct-care staffing level, and funding sources (Liu, Feng, & Mor, 2014).

Limited research on Chinese residential care facilities shows that the quality of care is concerning. For example, the direct care staff-to-resident ratio is typically low (Feng et al., 2011) and most staff do not receive adequate training (Feng, Liu, Guan, & Mor, 2012; Hao et al., 2012). Regulations are sketchy and not consistently implemented across China (Shum et al., 2015). Also, a quality-monitoring system is not in place (Feng et al., 2012). These system-level barriers posed challenges to achieving high-quality care in Chinese residential care facilities. Meanwhile, a paucity of research has focused on individual-level residents' care needs, including resident-perceived difficulties in accomplishing their daily care needs. Among challenges facing residents in Chinese residential care facilities, those related to functional limitations and pain have potentially substantial impact on their daily life, as indicated by evidence from other countries on the high prevalence of functional limitations and pain and their profound influence on residents' life (Takai, Yamamoto-Mitani, Okamoto, Koyama, & Honda, 2010). Therefore, the purpose of this dissertation is to advance our understanding of residents' care needs, particularly focusing on

describing residents' challenges with functional limitations and pain. This knowledge is essential to guide development of care strategies for future long-term care system in China.

### ***1.2 Functional Limitations and Pain in Residential Care Facilities***

Functional limitations and pain are prevalent among residents in residential care facilities globally. For example, a longitudinal study involving 377 nursing homes in the United States found that those with functional limitations accounted for over 90% of all residents (Wang, Kane, Eberly, Virnig, & Chang, 2009). The high prevalence of acute and chronic pain conditions (tooth pain, migraines, low back pain, neck pain, osteoarthritis, and so forth) has been noted as a global cause of disability, with chronic low back pain as the “single greatest cause of Years Lived with Disability” (Rice, Smith, & Blyth, 2016, p. 792). Extensive studies have reported the high prevalence of pain among older adults. For example, Patel et al. (2013) used a nationally representative sample of community-dwelling older adults in the United States and reported the pain prevalence of 53%. Evidence varies on pain prevalence among residents in residential care facilities; a systematic review reported that the prevalence of pain ranged from 23% to 80% (Takai, et al., 2010).

Functional limitations and pain are often interrelated in residents' daily lives. Studies from other countries have established the consequences of pain on various aspects of residents' daily life in residential care facilities. Pain is associated with decreased physical function (Patel et al., 2013), higher prevalence of depression and anxiety (Kroenke et al., 2011), impaired cognitive function (Attal et al., 2014; Moriarty, McGuire, & Finn, 2011), loneliness and social isolation (Mort & Philip, 2014), and even suicide (Hooley, Franklin, & Nock, 2014). A qualitative study on residents' experiences of pain found that pain could lead to immobility and residents might

need to take more time to perform certain daily activities because of pain (Gran, Festvåg, & Landmark, 2010). Some older adults reduced activities to avoid exacerbation of pain (Mackichan 2013). So, it is important to understand, to what extent functional limitations and pain might be a significant problem in the context of Chinese residential care facilities.

### ***1.3 Management of Functional Limitations and Pain in Residential Care Facilities***

Extensive research has examined various approaches to managing pain. Commonly cited pain management approaches include traditional western medicine (Knopp-Sihota, Patel, & Estabrooks, 2016), complementary therapies that are used in conjunction with traditional pain medicine (Houzé, El-Khatib, & Arbour, 2017), alternative therapies in place of traditional pain medicine, and psychological interventions (Adachi, et al., 2014). Also, guidelines have been developed that direct health care professionals how to care for residents with functional limitations and pain. For example, the American Medical Directors Association (AMDA) published the guideline for “Pain management in the long-term care setting”; steps are listed regarding how to approach comprehensive pain assessment and management (American Medical Directors Association, 2012).

Residents commonly engage in efforts to manage functional limitations and pain by themselves, and these efforts are referred to as residents’ self-management strategies. Some of their self-management strategies might be consistent with the recommended approaches based on evidence. In a study in Taiwan nursing homes, residents used different pain management strategies, including pain medication, massage, and taking Traditional Chinese Medicine (Tsai, Tsai, Lai, & Chu, 2004; Tsai, Wei, Lin, & Chien, 2005). Residents might also adopt self-management strategies that are not supported by available evidence. For example, studies have

identified “ignoring the pain” as a commonly used strategy by residents (Gillsjö et al., 2012; Mackichan, Adamson, & Gooberman-Hill, 2013).

Various environmental factors have been reported that interfere with adequate pain management in long-term care settings. For example, a review of barriers to pain reporting revealed that poor communication between nurse aides and residents led to residents not being listened to or not being understood (Gammons & Caswell, 2014). A qualitative study on residents’ experiences with pain found that waiting for staff help could indirectly intensify residents’ pain (Gran et al., 2010). In addition, frontline workers’ lack of motivation could stop staff from engaging residents with pain in performing functional tasks; the lack of motivation results from a lack of training, inadequate staffing, and fear of adverse events (falls et al.) (Resnick, Galik, & Boltz, 2013). Because frontline workers play a central role in initiating and implementing pain management (Holloway & McConigley, 2009), it is important to understand staff characteristics and the care they currently provide that relates to residents’ functional limitations and pain. Doing so will inform care strategies to achieve improved quality of care in the future development of Chinese residential care facilities.

#### ***1.4 Purpose Statement and Aims***

The overall purpose of this dissertation is to develop knowledge of residents’ care needs in Chinese residential care facilities, focusing on functional limitations and pain. Knowledge gained will be essential to inform the development of innovative care strategies and achieve improved quality of care in residential care facilities in China.

To guide this exploration, we adopted the Adaptive Leadership Framework, which was first used to understand organizational changes in the business field (Heifetz, 2009). When

applied to the management chronic illnesses, it provides a new lens for looking at the patient-provider relationship, by proposing that patients and their formal and informal caregivers need to be supported in their efforts related to disease management (Anderson et al, 2015). This framework has five key concepts: technical challenge, adaptive challenge, technical work, adaptive work, and adaptive leadership.

Technical challenges are those difficulties that could be clearly defined, and there are straightforward approaches (technical work) to address these challenges. Adaptive challenges encompass difficulties that need to be understood within the local context and solving the challenge requires the person who owns the challenge to adapt to the situation. Such adaptation might include changing a mindset, learning new skills, or developing new behaviors (which would be called “adaptive work”). Challenges often involve both technical and adaptive components. One example of a challenge might be that residents feel they have no one to talk to in residential care facilities. The technical component of this challenge might be the functional impairments that prevent residents from moving around and making friends. The adaptive component might be that residents resist interacting with other residents who are new to them. Staff might help residents to move around by providing assistance with mobility (which would be called “technical work”). Residents might need to change their expectations and start to interact with other residents (an example of adaptive work). Staff could also facilitate residents’ interaction by helping them connect with other residents (an example of staff using adaptive leadership). Facilities could further facilitate these interactions by providing physical facilities where social interactions could easily happen (an example of a facility using adaptive leadership).

By differentiating between technical and adaptive components of challenges; the Adaptive Leadership Framework will inform different corresponding strategies to address each of



the two components. Also, the framework differentiates between technical and adaptive work, some examples of which were given above. Understanding required technical work in the local context will guide the preparation of staff expertise to integrate technical work in their training; identifying what is potentially needed adaptive work will guide efforts to integrate different stakeholders to come up with solutions. In addition, the framework proposes supporting residents and staff in implementing their work. Identifying gaps in the support will inform potential areas to focus on at the facility and long-term care system levels in long-term care development.

The overall purpose of this dissertation will be accomplished via five overall aims, with each chapter representing one aim. Each aim is guided by the Adaptive Leadership Framework.

### **1.3.1 Chapter 1 Aim**

Introduce the problem and significance.

### **1.3.2 Chapter 2 Aims**

In Chapter 2, a systematic literature review was conducted that analyzed and synthesized literature on current staff and care provided in Chinese residential care facilities, as part of organizational context, within which residents experience challenges with functional limitations and pain. This review described, in Chinese residential care facilities, 1) staff characteristics and the care they provide, 2) resident characteristics and care needs, and 3) the role of family members in resident care.

### **1.3.3 Chapter 3 Aims**

In Chapter 3, a qualitative observational study was conducted to explore residents' challenges with physical function in Chinese residential care facilities.

### **1.4.4 Chapter 4 Aims**

In Chapter 4, a mixed-methods, observational study was conducted to describe, in Chinese residential care facilities, residents' challenges with pain and functional limitations, residents' and frontline workers' efforts to manage these challenges. Specific aims are:

**Aim 1:** Describe residents' self-reported pain characteristics and physical function (quantitative strand).

**Aim 2:** Describe, from residents' perspectives, challenges with pain and functional limitations, residents' self-management strategies, and frontline workers' strategies to manage these challenges (qualitative strand).

**Aim 3:** Describe, from residents' perspectives, challenges with pain and functional limitations, residents' self-management strategies, and frontline workers' strategies at different functional levels and by pain characteristics (mixed aim).

#### **1.4.5 Chapter 5 Aims**

In Chapter 5, I highlight the implications of the three papers, relate overall findings to the Adaptive Leadership Framework, and provide implications for practice, policy, and research.

## **2. Staff Characteristics and Care in Chinese Nursing Homes: A Systematic Literature Review**

### ***2.1 Introduction***

By 2050, the number of people aged 60 years and older in China is expected to reach 450 million, accounting for 33% of its total population (Wong & Leung, 2012). Among this rapidly aging population, the group of elders aged 80 and older, known as “oldest old,” is the fastest growing, leading to an increasing demand for long-term care (LTC) services (Zhan, 2013). However, increasing migration from rural to urban areas, especially among young people, and the shrinking average family size due to China’s one-child policy have overwhelmed traditional, informal family-based caregiving model for older adults, especially the “oldest old.” (Wong & Leung, 2012; Zhan, 2013) These factors have created a great demand for formal LTC services in China, including nursing homes (NHs), —a need that has emerged recently and is in the initial stages of development (Wu et al., 2009). There is no standardized definition for NHs in Mainland China. Different terms are used, such as old age home, retirement apartment, residential care facilities, welfare institutes, and geriatric hospital. For this paper, NHs were defined as residential LTC facilities in Mainland China that mainly admit people who are 60 years and older. Thus, as defined in this paper, NHs include various types of institutions that provide LTC services for older adults with different functional levels (Zhan, Luo, & Chen, 2012). This definition was used because we aimed to provide an understanding of the current situation of various formal residential LTC services in Mainland China.

Because LTC facilities are a newly emerging care option in Mainland China, the workforce is poorly developed and under-prepared. For example, studies about Chinese NHs consistently report an extreme lack of qualified NH workers at all levels, including direct caregivers, administrators and nursing and medical professionals (Chu & Chi, 2008; Feng et al.,

2012; Hao et al., 2012). In one review, Chinese NHs not only were insufficient in quantity in comparison with developed countries, but also varied a lot in quality of care provided (Feng et al., 2012). Most direct caregivers in Chinese NHs received little training in nursing and caregiving skills or no training at all (Hao et al., 2012; Zhang, 2007). In addition, Chinese NHs had few qualification standards for staff preparation for their roles in NHs (Feng et al., 2011; Hao et al., 2012; Wu & Caro, 2009; Wu et al., 2012). Formal LTC is an emerging industry in China, thus the opportunity exists to develop staff training programs from the ground up using patient (resident) centered care approaches (Burman et al., 2013; Morgan & Yoder, 2012), using the most advanced knowledge from other countries.

In order to develop staff training programs, we need to synthesize the literature for what is known about characteristics of staff who are providing care, and what services they provide in Chinese NHs. The characteristics of NH staff have been extensively researched in other countries in studies of staff demographics and educational preparation and how these characteristics influence resident outcomes in NHs. For example, an interventional study in 3 NHs in the U. S. found that resident oral health was improved after training certified nurse aide about mouth care (Sloane et al., 2013). A qualitative study about end-of-life care in NHs in UK found that staff expertise about end-of-life care and their strong relationships with residents facilitated end-of-life care for residents with dementia (Livingston et al., 2012). Also, an interventional study involving education and problem-solving support for Registered Nurses in 45 NHs in German was reported to reduce the use of physical restraints in NH residents (Koczy et al., 2011). Knowing the characteristics of NH staff in Mainland China will direct areas for future research to improve resident outcomes.

Staff characteristics also have been linked to work outcomes in NHs. For example, a survey of 572 NH staff in Sweden found that direct caregivers who received no education about care, medicine, or social support reported higher workload, more communication obstacles, poorer sleep, and more stress symptoms compared with those who completed at least 10-20 weeks of education on care, medicine, and social support (EngstrÖM et al., 2011). A survey of 804 staff in 21 Swiss NHs found that staff use of recommended measures in response to residents' aggressive behaviors was related to their training on aggression management, employment level, and professional experience (Zeller et al., 2014). So it is important to know about characteristics of NH staff and the care they provide to develop training programs for NH staff and ultimately improve both resident and staff outcomes.

Similarly, it is also timely and necessary to synthesize evidence about characteristics of residents, their care needs, and the types and levels of care that should be provided in NHs, in order to guide studies to develop empirically supported, resident-focused care strategies to inform staff training programs. Understanding resident's characteristics and synthesizing knowledge about resident care need are also key components to knowing how to guide future research for developing resident-centered care approaches in Mainland China.

Finally, we need to understand how NHs currently involve families and/or the role of family members in providing NH care for residents so that these relationships might be incorporated into workforce training and NH system planning. Studies from other countries reported various roles that family members play in resident care in NHs. For example, a qualitative study found that family members assumed roles as advocators for residents in NHs because of their fears of poor quality of care, or negative experiences with NHs (Shield, Wetle, Teno, Miller, & Welch, 2010). Synthesizing knowledge about roles of family members in

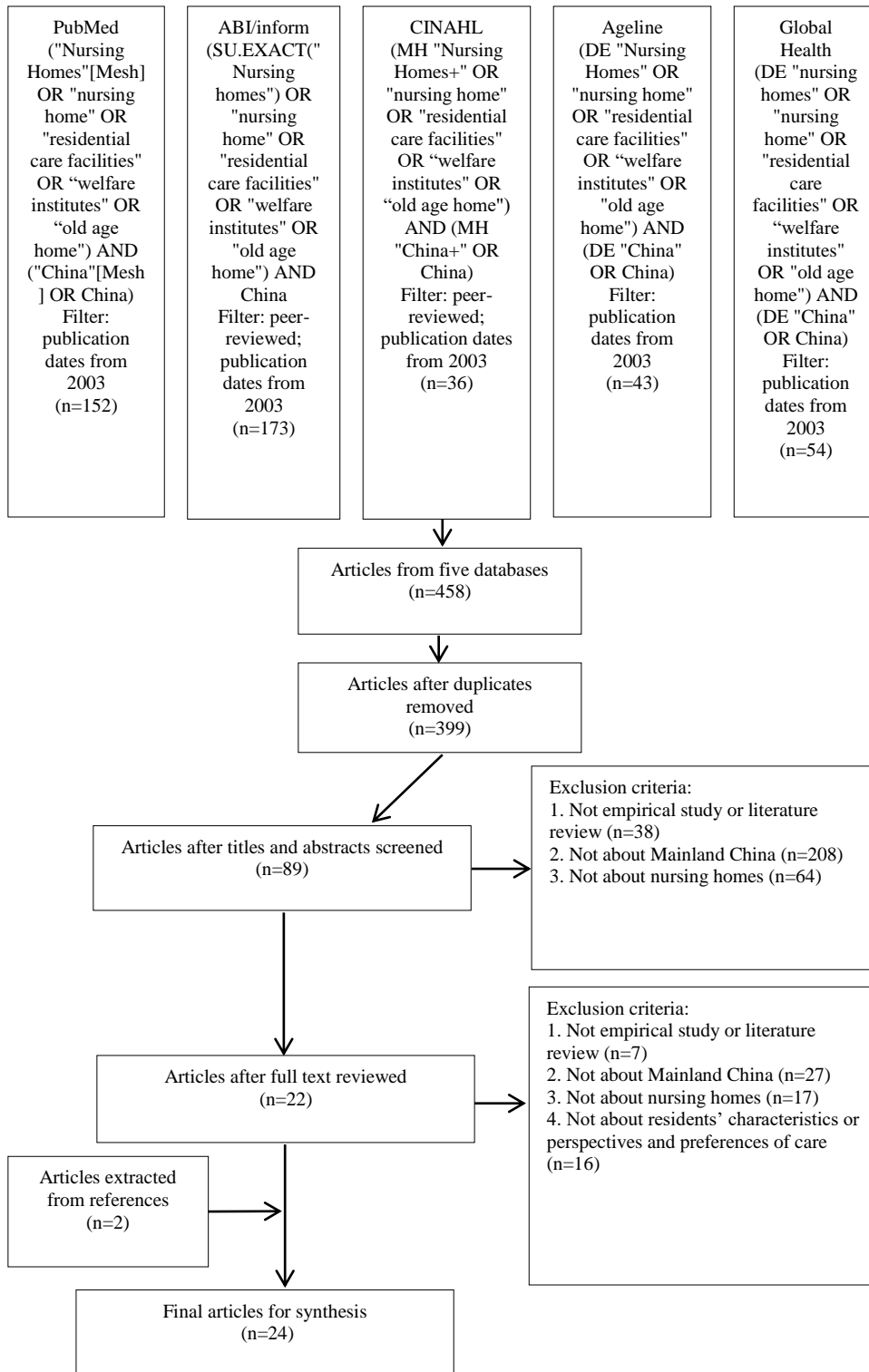
Chinese NHs is also important to facilitate family members' psychological well-being. For example, a qualitative study suggested that involving family members as partners in resident care would facilitate family members' adaptation to residents' institutionalization (Graneheim, Johansson, & Lindgren, 2014).

This literature review, therefore, aims to provide a systematic understanding of characteristics of the current workforce and care they provide in Chinese NHs, as well as residents' characteristics and care needs, and family roles in providing resident care. Knowledge gained in this literature review will guide future research of Chinese NH workforce development, and guide the development of workforce training programs to prepare the workforce to provide competent and safe care in Chinese NHs.

## **2.2 Method**

As depicted in the flow chart (see Fig. 1), PubMed, ABI/inform, CINAHL, Ageline, and Global Health were searched, using “nursing home,” “residential care facilities,” “welfare institutes,” “old age home” and “China” as search terms. Seeking a broad search of the literature, we used both controlled vocabulary and text keywords as search terms. We limited publication dates to 2003-2013 because this is the era in which NHs began to proliferate in China and changes in the NH care sector have been very rapid, deeming older research less relevant. The “peer-reviewed” filter was applied in ABI/inform and CINAHL. We did not apply a language filter because all retrieved articles were written in English or Chinese, both of which the first author is able to understand. A total of 458 articles were obtained from five databases. After duplicates were removed, 399 articles remained. By reviewing titles and abstracts, we excluded articles that were not empirical studies or literature reviews or that were not about NHs in Mainland China. We excluded Hong Kong and Macao (also named Macau) because their

development of LTC is quite different from that of Mainland China; they were influenced deeply by western cultures during the extended colonial period and have retained a high degree of autonomy under the “one country, two systems” arrangement since their reunification with China in the 1990s. We also excluded Taiwan because the healthcare systems are quite different between Taiwan and Mainland China. Included articles were screened in more detail by scanning full text, and again we eliminated articles that were not empirical studies or literature reviews, or that were not about NHs in Mainland China. Also, we excluded articles that were not about residents’ characteristics or that were not about care in NHs. The first author made the initial determination of which articles to include or exclude. To verify, the second and third authors reviewed all of the inclusion and exclusion decisions. Disagreements were discussed and resolved among authors. At the end of this search process, we retained 22 articles. We then reviewed the reference lists of all the retrieved articles using a snowballing technique that returned 2 additional articles for this paper, resulting in 24 articles for the review.



Note. ABI/inform=American business index, CINAHL= Cumulative Index to Nursing and Allied Health Literature.  
 Fig. 1- Flow diagram of inclusion and exclusion of articles.



To get a complete understanding of staff and resident characteristics and NH care in Mainland China, we also searched the Chinese database CNKI (the China National Knowledge Infrastructure), using yanglaojigou, yanglaoyuan, laoniangongyu, fuliyuan, jinglaoyuan, huliyuan, and laonianyiyuan (residential care facilities, elder care home, apartment for the elderly, welfare institute, home of respect for the elderly, nursing home and geriatric hospital respectively) as search terms (see Fig 2). We again limited publication dates to 2003-2014. We also limited the search to core Chinese journals, a criteria for quality of journals that is commonly used in Mainland China, in order to ensure the high quality of articles included into this review (Hou, 2012); a total of 299 articles were obtained. By reviewing titles and abstracts, we excluded articles that were not empirical studies or systematic literature reviews, and 90 articles remained. Included articles were screened in more detail by scanning full text. We eliminated articles that were not empirical studies or systematic literature review, that were not about resident characteristics or NH care, or that had insufficient description of the research methods to determine study design and analyses (i.e. having only limited information on methods section and/or variable selection). The first author made the initial determination of which articles to include or exclude, and the last author verified the inclusion and exclusion decisions. Disagreements were discussed and resolved among authors. At the end of this search process, we retained 21 articles in Chinese. Altogether, 45 articles were included into the review.

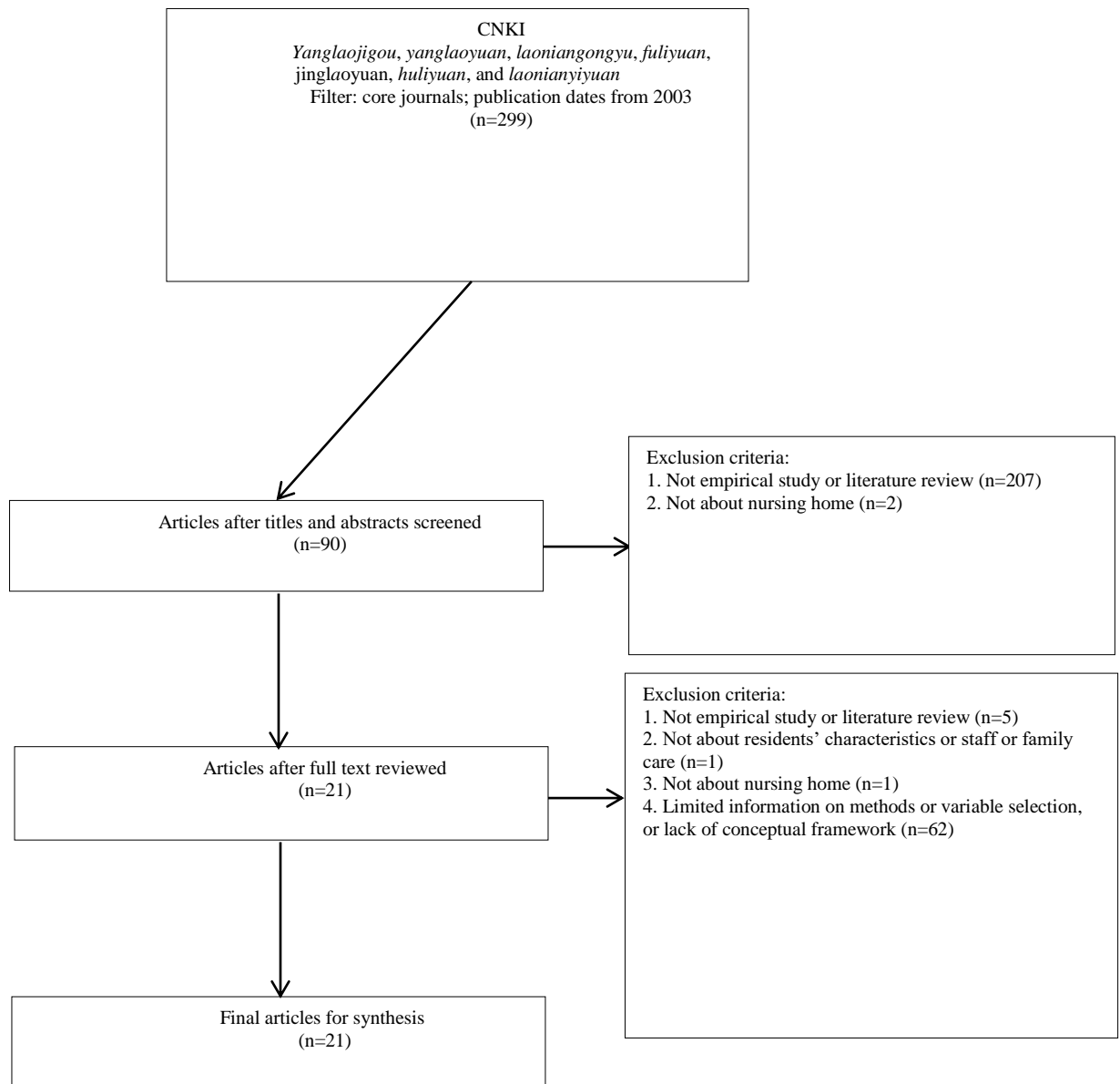


Fig. 2: Flow diagram of inclusion and exclusion of articles from one Chinese database.

We analyzed the retained articles using the matrix method (Garrard, 2011). The first author thoroughly read the articles, abstracted them into a matrix with 9 headings: titles, years of publication, authors, aims, terms used for NH, methods, sample/setting, themes and findings. This matrix was analyzed to identify themes among articles. All decisions were reviewed and verified by the other authors. Then we synthesized the findings by theme. Table 1 summarizes the study design, sample, setting and themes for each included article.

Table 1

*Summary of Articles*

Author	Research design	Data sources/sample	Setting	Themes
Zhan, Liu, and Bai (2005)	Secondary data analysis	265 residents	67 NHs; Tianjin	Staff characteristics and care provided: care by NH staff. Residents' characteristics and care needs: age. Residents' characteristics and care needs: age, chronic diseases and functional status. Care by family members.
Gu, Dupre, and Liu (2007)	Secondary data analysis	CLHLS: three waves (1998, 2000 and 2002)	Half of counties/cities within 22 provinces	Staff characteristics and care provided: care by NH staff. Residents' characteristics and care needs: functional status. Care by family members.
Li and Buechel (2007)	Survey	101 Chinese and 63 American family members of NH residents	Mainland China and greater Cincinnati areas, U.S.	Staff characteristics and care provided: care by NH staff. Residents' characteristics and care needs: functional status. Care by family members.
Wang, Shi, and Gao (2007)	Survey	379 residents	A provincial-level NH; Guangzhou	Staff characteristics and care provided: care by NH staff. Residents' characteristics and care needs: functional status. Residents' characteristics and care needs: age and psychological well-being.
Wu, Mao, and Xu (2008)	Interview, review of policy documents and literature	Elderly residents, administrators, policy-makers and governmental officials and researchers	12 NHs; rural areas of Hubei and Shanghai	Staff characteristics and care provided: care by NH staff. Residents' characteristics and care needs: functional status. Residents' characteristics and care needs: functional status.
Li, Zhang, and Liang (2009)	Secondary data analysis	CLHLS: first two waves (1998, 2000)	Half of counties/cities within 22 provinces	Staff characteristics and care provided: care by NH staff. Residents' characteristics and care needs: functional status and cognitive status and psychological well-being.
Wu and Caro (2009b)	Interview, review of policy documents and literature	30 elderly residents, 12 NH staff and 12 NH administrators	12 NHs; rural areas of Hubei and Shanghai	Staff characteristics and care provided: staff demographics and staff qualification standards.

Wu, Mao, and Zhong (2009)	Literature review	Number of included articles not provided	Rural China	Residents' characteristics and care needs: age, chronic diseases and functional status. Staff characteristics and care provided: staff demographics and care by NH staff. Residents' characteristics and care needs: functional status.
Wu, Low, Xiao, and Brodaty (2009)	Assessment and interview	149 residents and their informal caregivers	1 NH, Shanghai; 3 ethno-specific Chinese NHs, Sydney; 4 mainstream NHs, Sydney	Residents' characteristics and care needs: cognitive status and psychological well-being.
Chen (2011)	Interview	11 elderly residents	1 NH; Shanghai	Care by family members. Residents' characteristics and care needs: functional status and psychological well-being.
Cheng, Rosenberg, Wang, Yang, and Li (2011)	Interview	27 elderly residents, 16 family members and 5 RCF managers	6 NHs; Beijing	Care by family members. Staff characteristics and care provided: staff demographics, staff qualification standards and care by NH staff. Residents' characteristics and care needs: functional status.
Feng et al. (2011)	Secondary data analysis	Interviews with NH administrators and query of local government websites	140 NHs; urban area of Nanjing	Residents' characteristics and care needs: functional status.
Lin, Wang, and Jia (2011)	Survey	133 residents	2 NHs; Shanghai	Residents' characteristics and care needs: cognitive status.
Wang, Hou, and Xu (2011)	Physical examination, lab measures	240 residents	2 NHs; Wenzhou	Residents' characteristics and care needs: chronic diseases.
Zheng, Hua, and Chen (2011)	Survey (questionnaire)	464 residents	20 NHs; Xi'an	Residents' characteristics and care needs: psychological well-

Feng, Liu, Guan, and Mor (2012)	Review of policy documents and literature	N/A	Both urban and rural China	being. Residents' characteristics and care needs.
Guo et al. (2012)	Interviews, medical history review and clinical physical examination	264 residents	4 NHs and 2 veteran care homes; Xi'an	Residents' characteristics and care needs: cognitive status.
Hao et al. (2012)	Survey (questionnaire)	Residents, nursing staff and manager	10 nursing agencies; Chengdu	Staff characteristics and care provided: staff demographics, staff qualification standards and care by NH staff. Residents' characteristics and care needs: age, chronic diseases, functional and cognitive status.
Liu, Dupre, Gu, Mair, and Chen (2012)	Secondary data analysis	CLHLS: three waves (1998, 2000, 2002)	Half of counties/cities within 22 provinces	Residents' characteristics and care needs: age, chronic diseases, cognitive status and psychological well-being. Care by family members.
Wu et al. (2012)	Qualitative (focus groups)	49 participants, including 10 residents	Jinan	Staff characteristics and care provided: staff qualification standards and care by NH staff. Residents' characteristics and care needs: age and psychological well-being.
Zhou and Ma (2012)	Survey	160 residents	1 NH; urban area of Shanghai	Residents' characteristics and care needs: age and psychological well-being.
Liu et al. (2013)	Survey	317 residents	15 of 27 NHs; Urumuqi	Residents' characteristics and care needs: age.
Song, Wang, and Yuan (2013)	Survey	230 residents	11 NHs; Chongqing	Residents' characteristics and care needs: cognitive status.
Sun et al. (2013)	Survey	427 residents	Tianjin	Residents' characteristics and care needs: age, and functional and

Ge, Zhang (Ge et al., 2011)	Qualitative interview	44 residents	7 NHs; Beijing	cognitive status. Residents' characteristics and care needs: age and chronic diseases Residents'
Liu, Dou (Liu et al., 2014)	Survey	1396 residents	44 NHs; Xinjiang	characteristics and care needs: demographics and chronic diseases Staff characteristics and care provided: staff demographics and qualification standards Residents'
Li, Song (Li, Song, & Li, 2014)	Survey	252 staff	38 NHs; West of Liaoning Province	characteristics and care needs: demographics and psychological well- being Residents'
Zhu, Wang (Zhu, Wang, Mao, Li, & Guo, 2006)	Survey	546 <i>wubao</i> elders	2 NHs; Hubei	characteristics and care needs: demographics and psychological well- being Residents'
Zhang, Lv (Zhang et al., 2012)	Survey	1193 residents	18 NHs; Hengshui, Hebei	characteristics and care needs: demographics, chronic diseases, physical function, and psychological well- being Residents'
Chen, Tang (J. Chen et al., 2012)	Survey at two time points	1036 residents	Urban and rural Guangzhou	characteristics and care needs: demographics, and cognitive status Residents'
Hua, Xu (Hua et al., 2014)	Survey	298 residents	9 NHs; Xuzhou	characteristics and care needs: demographics Residents'
Zhao, Ma (Zhao, Ma, Yu, & Zhu, 2007)	Survey	163 residents	4 NHs; Shanghai	characteristics and care needs: demographics, physical function, and cognitive status Residents'
Liu, Zhou (Liu, Zhou, & Liu, 2012)	Survey	2059 residents	32 NHs; Shanghai	characteristics and care needs: demographics and psychological well- being Residents'
Zhang, Cen	Survey	289 residents and 526	10 NHs; Kunming	Residents'

(Zhang, Cen, & Guo, 2010)		community-dwelling older adults		characteristics and care needs: demographics, physical function, cognitive status, and psychological well-being Residents' characteristics and care needs: demographics, chronic diseases, and psychological well-being
Yi, Yan (Yi & Yan, 2006)	Survey	206 residents and 620 community-dwelling older adults	25 NHs; Shenzhen	Residents' characteristics and care needs: demographics, chronic diseases, and psychological well-being
Xu, Cong (Xu et al., 2010b)	Survey	665 residents	21 NHs; Nanjing	Residents' characteristics and care needs: chronic diseases
Xu, Cong (Xu et al., 2010a)	Survey	665 residents	21 NHs; Nanjing	Residents' characteristics and care needs: demographics
Zhang, Lu (Zhang, Lu, Guo, & Hao, 2014)	Survey and health examination	241 residents	1 NH; Weifang	Residents' characteristics and care needs: demographics, chronic diseases, and physical function
Li, Xu (Li & Xu, 2011)	Survey	106 NH direct caregivers	2 NHs	Staff characteristics and care provided: staff demographics and care by NH staff
Zhang, Liang (Zhang, Liang, & Chen, 2008)	Survey	242 residents	2 NHs; Guangzhou	Residents' characteristics and care needs: demographics
Wu, Dong (Wu, Dong, Ding, Chen, & Pang, 2011)	Survey	356 residents and 60 NH staff	10 NHs; Chengdu	Residents' characteristics and care needs: cognitive status Staff characteristics and care provided: staff demographics, qualification standards, and care by NH staff
Gu, Liu (Gu & Liu, 2006)	Secondary data analysis	1205 residents and 23530 community-dwelling older adults	CLHLS: three waves (1998, 2000 and 2002)	Residents' characteristics and care needs: demographics
Wu, Li (Wu	Focus group	9 government	Jinan	Staff characteristics



et al., 2010)		officials, 10 NH managers, 10 NH staff, 10 residents, and 10 community-dwelling older adults		and care provided: staff demographics, psychological well-being, qualification standards, and care by NH staff Residents' characteristics and care needs:
Xiao, Algase (Xiao et al., 2004)	Survey and video recording	NH staff and 20 residents	2 NHs; Beijing and Guangzhou	demographics and cognitive status Staff characteristics and care provided: care by NH staff
Huang, Zhang (Huang, Zhang, & Yin, 2012)	Survey	556 direct caregivers and 16 nurses	30 NHs; Liaoning	Staff characteristics and care provided: demographics and qualification standards

*Note.* NH=nursing home.

### **2.3 Results**

Our synthesis of the reviewed articles about resident characteristics and care in Chinese NHs is presented in three themes: staff characteristics and care provided, resident characteristics and care needs, and care by family members.

#### **2.3.1 Staff Characteristics and Care Provided**

##### **2.3.1.1 Staff demographics**

Nine studies reported demographic characteristics of staff in Chinese NHs, including age, gender, education level, and sources of staff. The age of NH direct caregivers generally ranged from 40 to 60 years of age and older; they are primarily women and have little formal education. Hao et al. (Hao et al., 2012) found that the mean age of direct caregivers was 52 years and 73% of them were female. Wu and Caro (Wu & Caro, 2009) reported that almost all direct caregivers were in their 40s to 50s and some were in their 60s. This study also found that 70% of NH administrators only had junior high school degrees (Wu & Caro, 2009). For direct caregivers, 76% of them were illiterate or had only primary school education (Hao et al., 2012). One study

describing the quality of care for residents with dementia found that none of the sixty direct caregivers had an education level higher than middle school (Wu, Dong, Ding, Chen, & Pang, 2011). However, two studies presented very different findings, including a younger age range of 30-53 (Huang, Zhang, & Yin, 2012; Li, Song, & Li, 2014) and a higher education level (e.g., bachelor degree) (Li et al., 2014). These findings among studies likely result from inclusion of diverse types of NHs (e.g., geriatric hospital versus apartment for elderly) or inclusion of NH staff with different job titles. In terms of sources of NH staff, most direct caregivers in urban areas were migratory workers from rural area (Feng et al., 2011; Hao et al., 2012; Wu et al., 2009; Wu et al., 2010). In rural areas, direct caregivers were from local areas, which were very likely the same village or community with residents (Wu & Caro, 2009; Wu et al., 2009). Also, for NHs of rural areas, many current administrators used to be direct caregivers (Wu & Caro, 2009; Wu et al., 2009). One of the nine studies addressed staff responses to working conditions, reporting that most direct caregivers knew little about psychological problems that might develop from their working conditions and suggesting more attention on helping staff detect and manage potential psychological problems, although it was not stated who should take the responsibility (Wu et al., 2010). The problem of psychological well-being of staff has been found to influence quality of patient care in other countries (McHugh, Kutney-Lee, Cimiotti, Sloane, & Aiken, 2011).

In terms of the quality of this group of studies, they included NHs in both rural and urban areas and in both developed and less developed regions of China. Two studies used cluster random sampling method to select NHs, in order to establish representative data (Hao et al., 2012; Li et al., 2014). However, NHs in the other seven studies used convenience sampling; findings, therefore, might not generalize to other NHs in the same geographic region or to Mainland China.

Also, the nine studies covered only limited characteristics of NH staff; In addition, none of the studies explored the relationship between staff characteristics and resident or family outcomes.

In summary, the studies provided some evidence about staff demographic characteristics in Chinese NHs such as age and gender, education, and sources of staff. Further descriptive research is needed to establish representative data on a variety of staff characteristics, including their physical and mental health status. This is important to identify challenges that NH staff might have in providing resident care, and to target workforce training programs to NH staff of specific characteristics. Also, more studies are needed to describe characteristics of not only direct caregivers but also staff of other job positions.

#### **2.3.1.2 Staff qualification standards**

Eight of the 24 studies addressed job qualifications for NH staff and reported that the few existing standards for qualifications varied widely across cities in China. Wu and Caro found no specific requirements for workforce training, or monitoring of quality of care. Most of the NH staff received little professional training in elder care (Hao et al., 2012; Huang et al., 2012; Li et al., 2014; Wu et al., 2011). Newly recruited direct caregivers were trained mainly by more experienced staff which did not follow standardized or knowledge-based training plans (Wu et al., 2010; Wu et al., 2012). Existing training programs, regardless of being led by NHs, government agencies, or Bureau of Civil Affairs, focused on providing daily care and basic knowledge about common diseases among older adults (Huang et al., 2012). Wu and Caro also reported regional differences of staff training, in which few staff in Hubei had received any training, while some staff in Shanghai in participating NHs received training and working certificates. Feng et al. (2011) found that less than one-third of the participating 140 NHs in Nanjing employed professional nurses or physicians. Despite this widespread lack of training,

some evidence suggests that staff welcome more care knowledge and skills; one study found that 96% of enrolled staff were willing to participate in training and desired training in basic knowledge about common diseases among older adults, and knowledge about psychological care and daily care (Huang et al., 2012).

In terms of the quality of this group of studies, they provided strong evidence that NHs had few job qualification standards for staff and there was little consistency in how staff was prepared for roles in NHs. The studies used both quantitative and qualitative designs. The four studies that used quantitative designs reported using random sampling (Hao et al., 2012; Huang et al., 2012; Li et al., 2014; Wu & Caro, 2009). Also, the eight studies provided data on staff training levels of both government-owned and private-owned NHs, as well as NHs in both urban and rural China. However, articles reviewed on training levels were mainly limited to direct caregivers; only one study mentioned the extreme lack of medical and nursing professionals in NHs (Feng et al., 2011).

These findings suggested that training standards and qualifications is a high priority area of research and policy development. Using western standards about qualifications of NH staff, we suggest that the qualifications of staff are not sufficient in Chinese NHs (Tyler, Jung, Feng, & Mor, 2010), but research is needed to support what will optimize staff and resident outcomes in China. Research is also suggested to set standards about what constitutes the necessary qualifications for unlicensed direct caregivers and how these might be obtained in both urban and rural China. The synthesis of the eight articles suggests research is needed to describe and evaluate existing staff training programs. In addition, because little is known about barriers to developing a qualified workforce, we suggest additional research to understand perspectives of

NH administrators, nursing leaders, and government officials about facilitators and barriers of NH staff training, in order to develop training programs for unlicensed direct caregivers.

### **2.3.1.3 Care by NH staff**

Eleven of the 24 articles reported findings about resident care provided by staff in Chinese NHs and reported that a range of care services were provided, but care was not individualized. Basic services were provided, including personal care, basic medical care, room cleaning, meals, and laundry (Hao et al., 2012; Wu et al., 2010; Wu et al., 2012; Wu et al., 2011). Wu et al. (2009) found four different care levels in participating NHs; they classified residents by the level of independence, ranging from totally independent to totally dependent in daily living. Studies found that care was lacking in both quantity and quality; there were few differences in skill levels of staff caring for residents who required different levels of assistance (Heying J. Zhan, Liu, & Bai, 2005). Lack of competent staff also was identified as a contributing factor to NHs denying admission to older adults who had functional dependency, cognitive impairment, or infectious disease (Wu et al., 2009; Wu et al., 2011). Each NH in rural China had a small clinic with a few non-prescription drugs that were used to treat most of residents' illnesses (Wu, Mao, & Xu, 2008). However, some residents' chronic conditions were neglected (Wu et al., 2008). Wu et al. (Wu et al., 2012) found that NHs differed from each other in amenities provided, instead of types and levels of care provided. None of the 10 surveyed NHs in Chengdu had a nutritionist to design individualized diet plans for residents (Hao et al., 2012). Also, less than one third of all NHs in the city of Nanjing employed nurses or physicians (Feng et al., 2011). Nonetheless, Li and Buechel (2007) found that family members had a high level of overall satisfaction towards residents' life in Chinese NHs, in terms of accessibility of nurses and quality of care, even higher than that in the U.S. NHs. Four studies reported challenges at different levels that NH staff had in

providing care for residents; these included agitation behaviors of residents with dementia (Xiao et al., 2004), lack of time (Li & Xu, 2011), intense relationship of staff with family members of residents (Wu et al., 2010), and lack of respect and support from society (Wu et al., 2010).

In terms of the quality of this group of studies, these eleven studies include both quantitative and qualitative designs and include NHs of both rural and urban China. However, the overall strength of evidence was relatively low. For example, only one of the eight studies that used quantitative designs randomly selected participants (Hao et al., 2012); the other seven studies used purposive or convenience sampling to select NHs or participants, thus results might not generalize to NHs in the geographic region or Mainland China (Feng et al., 2011; Li & Buechel, 2007; Zhan et al., 2005). For the three studies that used qualitative designs, none stated explicitly how qualitative rigor was assured (Wu et al., 2008; Wu et al., 2010; Wu et al., 2012). Also, evidence about care provided by NH staff was very limited. For example, no studies examined residents' perspectives about care provided by NH staff. Only one study investigated family members' level of satisfaction towards care provided by NH staff, but no study explored the correlation between quality of resident care by NH staff and family members' level of satisfaction towards the care.

In summary, these eleven studies provided limited evidence about types of care provided by NH staff. Studies provided some evidence that care was lacking in both quantity and quality. However, in one study, family members had high level of satisfaction for resident care by NH staff. Thus, as a whole, these studies might indicate variation in quality of care provided by NH staff. Additional descriptive research is needed to describe in more detail types and levels of care by NH staff of different care roles, involving residents' and family members' descriptions and

preferences of resident care by NH staff. Also, research is needed to link care by NH staff with resident or family outcomes, in order to navigate and evaluate workforce training programs.

### **2.3.2 Resident Characteristics and Care Needs**

Three sets of resident characteristics were reported in this literature: 1) age, 2) chronic diseases, and 3) functional and cognitive status and psychological well-being.

#### **2.3.2.1 Age**

Twenty two of the 45 articles reported about the age of residents and again, the reports varied; percentages of participants who were 80 years and older, known as the oldest old, ranged from 22% to 100% (Gu et al., 2007; Hao et al., 2012; Hua et al., 2014; G. Liu, Dupre, Gu, Mair, & Chen, 2012; Liu et al., 2013; Sun et al., 2013; Wang, Shi, & Gao, 2007; Wu & Caro, 2009; Yi & Yan, 2006; Zhan et al., 2005; Zhang, Liang, & Chen, 2008; Zhang, Lu, Guo, & Hao, 2014; Zhang et al., 2012; Zhou & Ma, 2012). Thus, we have little definitive knowledge about ages of NH residents in China. Two studies reported characteristics of residents who were 80 years and older (Gu et al., 2007; Liu et al., 2012). They found that, in comparison with residents living in the community, “institutionalized oldest old are more likely to be younger, have lower family caregiving resources and exhibit poorer health,” (Gu et al., 2007; Liu et al., 2012) and these institutionalized older adults were reported to have more chronic diseases, less cognitive impairment and better psychological well-being in terms of positive affect, loneliness and quality of life than those living in the community (Liu et al., 2012).

In terms of study quality, six studies addressed selection bias of enrolled NH or resident participants; four studies used a random sampling method for participants (Hua et al., 2014; Wu & Caro, 2009; Zhang et al., 2008). Zhao et.al (2007) included all eligible residents. Liu et al. (2012) restricted analysis to newly enrolled older adults for each of the three waves of Chinese

Longitudinal Healthy Longevity Survey (CLHLS) data, which used random sampling in its original research design. However, the other sixteen articles did not address the issue of selection bias when selecting NH residents, making it uncertain whether the participants were representative of the population in each NH.

In summary, these findings indicated wide variability in percentages of the oldest old age group among NHs. Additional epidemiological studies are needed to establish representative data of the age of residents in Chinese NHs, including the percentage of oldest old.

### **2.3.2.2 Chronic diseases**

In this review, we defined chronic diseases as “diseases of long duration and generally slow progression.” (World Health Organization, 2013) Thirteen of the twenty one articles reported about chronic diseases among Chinese NH residents.

Nine of the twelve articles reported specific data in the percentage of residents with one or more chronic illnesses which varied widely, ranging from 50% to 94% (Hao et al., 2012; Hua et al., 2014; Wang, Hou, & Xu, 2011; Wu & Caro, 2009; Xu et al., 2010; Yi & Yan, 2006; Zhang, Cen, & Guo, 2010; Zhang et al., 2014; Zhang et al., 2012). The chronic diseases with highest prevalence were hypertension, coronary heart disease, stroke, and arthritis (Xu et al., 2010; Yi & Yan, 2006; Zhang et al., 2010; Zhang et al., 2014; Zhang et al., 2012). Two of the thirteen articles did not provide specific data about the rates of chronic illness but reported about chronic diseases only in general terms. Gu et al. (2007) reported that, in comparison with community-dwelling older adults, more NH residents reported having at least one chronic disease and Liu et al. reported that NH residents “had significantly more chronic diseases.” In addition, two articles reported management of chronic diseases by residents. Ge et al. (2011) reported that most female residents with urinary incontinence did not seek medical care, mainly because they did not



consider this as a chronic condition that needs medical intervention. Liu et al. (Liu et al., 2014) reported a low level of health literacy that might hinder effective self-care of chronic diseases.

This set of studies had both strengths and weaknesses. Nine articles provided specific data to describe diseases and prevalence among NH residents. Also, the enrolled NHs covered various ownership types, including government-owned, collective-owned and private-owned. However, three of the twelve articles did not define chronic diseases in their studies (Hao et al., 2012; Hua et al., 2014; Wu & Caro, 2009). Only three of the twelve articles addressed the issue of selection bias when selecting resident participants, making it uncertain whether findings from the other nine articles represented residents enrolled in NHs (Hua et al., 2014; Zhang et al., 2012). Further, studies used different data collection methods of chronic diseases among residents. For example, seven articles used self-report by residents (Gu et al., 2007; Hua et al., 2014; Liu et al., 2012; Wu & Caro, 2009; Xu et al., 2010; Yi & Yan, 2006; Zhang et al., 2010), and three used diagnosis by medical professionals (Hao et al., 2012; Wang et al., 2011; Zhang et al., 2014). Using these different sources of data provides some understanding of resident prevalence of chronic diseases, but it is not possible to compare results across studies, weakening what we know about prevalence of chronic diseases in NHs.

In summary, these studies presented widely varied results in their reports of prevalence of chronic diseases in Chinese NHs. Because research has yet to provide clear information about prevalence of chronic diseases, additional epidemiological studies are needed in order to plan for care needs. Also, we suggest that future studies use the same diagnosis standards and clear participant selection criteria to enable deeper understanding of prevalence of various types of chronic diseases among Chinese NH residents. Knowledge gained will inform content of workforce training programs to help with chronic disease management of NH residents.

### **2.3.2.3 Functional and cognitive status and psychological well-being**

In this review, functional status was defined using dependence level of activities of daily living (ADL), that is, “activities that people perform habitually and universally;” (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) cognitive function was defined as “the process by which an individual perceives, registers, stores, retrieves and uses information;” (Touhy & Jett, 2010, p.91) and psychological well-being was defined as mental wellness in six aspects including self-acceptance, environmental mastery, purpose in life, positive relations with others, personal growth, and autonomy (Ryff & Keyes, 1995). Twenty eight of the 45 articles reported data about resident physical and cognitive function and psychological well-being in Chinese NHs.

Eighteen articles provided specific and varied data about physical or cognitive function or psychological well-being among NH residents. Many residents were found to have a high functional level (Wu et al., 2009), higher than residents in the US (Li & Buechel, 2007). In terms of physical function, the percentage of residents with ADL limitations ranged from 15% to 81% (Feng et al., 2011; Gu et al., 2007; Hao et al., 2012; Wu & Caro, 2009; Zhang et al., 2010; Zhang et al., 2012), and one study found that NH residents were 1.9 times more likely to be ADL disabled than community-residing older adults (Gu et al., 2007). Wu et al. (2008) reported that usually less than 10% of older adults in their sample were bedridden or semi-bedridden and that not all NHs accepted such residents.

In terms of cognitive status of residents, studies reported the percentage of residents with cognitive impairment ranging from 13% to 66% (Gu et al., 2007; Hao et al., 2012; Song, Wang, & Yuan, 2013; Zhao et al., 2007), and one study found that NH residents were 1.6 times more likely to be cognitively impaired than community-residing older adults (Gu et al., 2007). More specifically, the percentage of residents with mild cognitive impairment ranged from 16% to 17%

(Song et al., 2013; Sun et al., 2013); the percentage of residents with moderate to severe cognitive impairment was 50% (Song et al., 2013); the percentage of residents with dementia ranged from 8% to 37% (Feng et al., 2011; Sun et al., 2013; Zhang et al., 2010). Also, three studies focused on the more specific population of residents with dementia. Xiao et al. (2004) described common agitation behaviors of residents with dementia. Chen et al. (2012) reported that the 8-year survival rates for residents with mild cognitive impairment and dementia were 17% and 4% respectively; severity of cognitive impairment was the influencing factor of 8-year survival rate. Wu et al. (2009) found that Shanghai NH residents with dementia had higher rates of behavioral symptoms compared to ethno-specific Chinese NH residents in Sydney, Australia.

In terms of psychological well-being, studies reported prevalence of depression which varied widely, ranging from 30% to 66% (Liu et al., 2012; Liu, Zhou, & Liu, 2012; Wang, Shi, & Gao, 2007; Yi & Yan, 2006). One study found that some residents reported significant improvements in psychological well-being after institutionalization, while others felt isolated and depressed (Cheng, Rosenberg, Wang, Yang, & Li, 2011). Studies also reported various influencing factors of psychological well-being, such as loss of spouse, illnesses, and satisfaction of care (Zhang et al., 2012; Zhu, Wang, Mao, Li, & Guo, 2006).

In terms of the quality of this set of studies, the twenty eight articles in this theme provided moderately strong evidence about physical and cognitive function among NH residents in both urban and rural China. Both descriptive and correlational research designs were used. However, only ten of the twenty eight studies used random sampling to select participants, thus findings from the other eighteen studies might not generalize to the geographic region or Mainland China. Also, considerable inconsistency existed between studies in the measures of physical or cognitive function, limiting the comparability of results. For example, physical

function was measured using a modified Barthel Index (Lin, Wang, & Jia, 2011), the Katz Index of ADL (Gu et al., 2007; Guo et al., 2012; Li, Zhang, & Liang, 2009) or SF-36 (Zheng, Hua, & Chen, 2011; Zhou & Ma, 2012). Although most studies used the Mini-Mental State Examination (MMSE) (Sun et al., 2013) to measure cognitive function, only 3 studies described their cut points for scores indicating cognitive impairment and dementia (Gu et al., 2007; Guo et al., 2012; Li et al., 2009). In addition, few of the articles explicitly stated definitions of psychological well-being variables, making comparisons between studies questionable.

In summary, this set of studies reported a relatively high functional level among NH residents in China as compared to functional levels of NH residents in western countries (Wang, Chang, Eberly, Virnig, & Kane, 2010; Wang, Kane, Eberly, Virnig, & Chang, 2009). This might result from different admission criteria, for example, individuals with pre-existing cognitive impairment or functional limitations might be denied admission, for Chinese NHs as compared to criteria used in western countries; this is an area for further study. More research is also needed to identify the best measures for physical function in order to compare results among studies. Also, longitudinal studies are needed to provide data about residents' trajectories of physical and cognitive function and psychological well-being in NHs, in order to inform what training and qualification is required for workforce.

### **2.3.3 Care by Family Members**

Four articles examined family members' roles in caring for NH residents; children played an important role in caring for NH residents. Most children continued to provide physical care, financial and emotional support to NH residents, as well as monitor and check the quality of care provided by NH staff (Cheng et al., 2011), and residents reported no differences in relationships with their children before and after institutionalization. Liu et al. (2012) found that associations

between institutionalization and better psychological health were moderated by the number of children, proximity and visits. However, in comparison with community-residing elders, NH residents had fewer family caregiving resources, indicated by lower percent of currently married, fewer number of living biological children and lower proximity with children (Gu et al., 2007).

In terms of the quality, the studies provided relatively strong evidence that family members played important roles in caring for NH residents. For example, both qualitative and quantitative designs were used. The two studies that used quantitative designs were both secondary data analysis of a nationally representative data set, thus findings could generalize to Mainland China (Gu et al., 2007; Liu et al., 2012). Of the other two studies that used qualitative designs, they did not provide any evidence about how qualitative rigor was assured (Chen, 2011; Cheng et al., 2011). Also, one study explored descriptions of the care provided by family members from various stakeholders' perspectives, including residents, family members and NH staff (Cheng et al., 2011), but did not present perspectives of the stakeholders separately, making it impossible to understand the commonalities and uniqueness of the three perspectives.

In summary, the four articles demonstrated the important roles that family members played in caring for NH residents. Qualitative studies describing family members' rational for why they provide so much care after a family member is admitted to a NH are needed to better understand how to support them. Also, qualitative studies involving the perspectives of residents are necessary to understand residents' experiences and explore their preferences of family support after institutionalization. Qualitative research is needed to explore staff experiences of family members' care for residents, in order to identify challenges they encounter with resident care by family members. Given the positive effects of care by family members on residents, family members and NH staff (Durkin, Shotwell, & Simmons, 2014; Pillemer et al., 2003; Port, 2006),

knowledge about current NH resident care by family members will inform staff training programs to effectively incorporate care by family members into NH care in order to provide high-quality resident care in NHs.

#### ***2.4 Discussion***

Studies found that most NH staff ranged from 40 to 60 years of age and older and they had little formal education; most direct caregivers in urban areas were migratory workers from rural area. Findings also indicated that direct caregivers were older, and had lower education levels in comparison with those in other countries. For example, using data of the U. S. National Nursing Assistant Study, Price-Glynn et al. (2012) reported that the average age of nursing assistants was 37, and most of them had high-school degree. Chan, et al. (2013) found that more than half of NH staff in Hong Kong had secondary level education (grade 7-12). The differences in age and education level of NH staff between Mainland China and other countries suggest a need for different staff training programs that address the specific characteristics of staff in Chinese NHs, because age and education level of trainees have been reported to influence the participation and uptake of training programs (Gegenfurtner & Vauras, 2012; Lakerveld et al., 2008; Quandt et al., 2013). For example, a meta-analysis found that age both influenced motivation to learn and moderated the relationship between motivation to learn and transfer of training (Gegenfurtner & Vauras, 2012).

Studies provided strong evidence that Chinese NHs had few qualification standards for staff training and there was little consistency between NHs and regions in how staff were prepared for their roles. The findings showed that the level of staff qualifications did not meet western standards, and more research is needed to determine what level of staff preparation is appropriate given the demand of care and the current constraints of resources in Mainland China.

For example, the U.S. Federal government mandates that all direct caregivers receive 75 hours of training before being certified to work in Medicaid/Medicare certified NHs (Tyler et al., 2010). Germany requires that at least 50% of all care staff are Registered Nurses who have had 3-year geriatric training (Harrington et al., 2012). Considering the significant role of workforce in healthcare delivery (Auerbach, Staiger, Muench, & Buerhaus, 2013) and the influence of workforce training on resident outcomes and staff working experiences (Han et al., 2014; Sloane et al., 2013), the sub-optimal staff qualification in Chinese NHs suggests this is a critical area for policy development to improve the capacity of Chinese NHs to provide competent and safe care.

Studies reported that the percentage of residents with ADL limitations ranged from 15% to 81%; they provided strong evidence that functional level of residents in Chinese NHs was higher as compared with functional level of NH residents in western countries. For example, a longitudinal study involving 377 NHs in Minnesota, United States found that the prevalence of NH residents who were totally independent in ADL was less than 10% (Wang et al., 2010; Wang et al., 2009). The huge difference in NH residents' functional level between Mainland China and western countries indicates that residents need different LTC services and thus training programs from other countries should be adopted with caution. However, the lack of longitudinal studies means there is little data for knowing the trends in functional level and if, as the NH system matures, it will admit residents with lower functional levels. Thus additional research is needed to know more about residents' need for LTC services in Chinese NHs in order to guide content-based workforce development programs.

A weakness of this set of studies was that they were limited to relatively developed cities in Mainland China, such as Shanghai and Xi'an. For example, eight of the included 45 studies sampled NHs in Shanghai and four sampled those in Guangzhou. Given the large proportion of

elder population living in rural China (Li, Chi, & Xu, 2013) and differences in the availability of LTC services between rural and urban China (Feng et al., 2012), additional studies are necessary to explore needs for LTC services among older adults in rural China. Thus, the evidence accrued in this literature review provides only a glimpse of the challenges that lie ahead for development of Chinese NHs but the evidence suggested numerous areas for future research.

#### **2.4.1 Limitations of the Literature Review**

One limitation of this review is that it is possible that we did not include all of the possible search terms because multiple terms are used to refer to NHs in China. To address this limitation, we used several terms including “nursing home,” “residential care facilities,” “welfare institutes” and “old age home” in English databases. In addition, we used both controlled vocabulary and text keywords as search terms in order to seek a broad search of the literature. In the Chinese database, we used several search terms including yanglaojigou, yanglaoyuan, laoniangongyu, fuliyuan, jinglaoyuan, huliyuan, and laonianyiyuan. Despite this limitation of this review, this analysis provides a necessary first step in synthesizing available knowledge about resident characteristics and care needs in Chinese NHs and thus will inform the next steps of research.

#### ***2.5 Conclusions and Implications for Research***

The lack of qualification standards of NH staff presented an urgent area for additional research into resident characteristics in Chinese NHs to help policy-makers establish qualification standards of staff to provide competent and safe care for NH residents in Mainland China. Several research questions have been derived from this literature review to suggest areas for additional research: (1) What are the characteristics of NH residents in Mainland China in comparison with those of NH residents in western countries, in terms of age, prevalence of chronic diseases,



functional and cognitive status and psychological-wellbeing? (2) What types and levels of care are preferred by residents and/or their family members? (3) What are staff characteristics in Chinese NHs, including direct caregivers, administrators and care professionals (such as physicians and nurses)? (4) In Chinese NHs that employ nurses, what is their role in providing care for residents? (5) What is the relationship between quality of care and nurses' demographics, education, and leadership behaviors in Chinese NHs? (6) What are the barriers of nurse's being employed in Chinese NHs? (7) What types and levels of care are provided in Chinese NHs as described by residents, their family members and NH staff? (8) What are the relationships between staffing characteristics/care by NH staff/care by family members and resident outcomes? (9) What are the staff training programs currently in place? How effective are these training programs in improving resident and/or staff outcomes?

### **3. Resident Challenges with Daily Life in Chinese Long-term Care Facilities: a Qualitative Pilot Study**

#### **3.1 Introduction**

Historically, families in China have provided long-term care (LTC) for older adults in their homes (Wong & Leung, 2012). Filial piety, a fundamental Confucianist philosophy, is a key virtue in Chinese culture (Lum et al., 2016). Due to the emphasis on respect for one's elders, China has always valued family-based care (Yeh, Yi, Tsao, & Wan, 2013). More recently, the 2012 *Rights Protection Law of Older Adults* upholds the central role of family and outlines the expectation that adult children will care for their aging parents (Zhan, Feng, & Luo, 2008; The Central People's Government of the People's Republic of China, 2012).

However, the traditional, family-based caregiving model no longer meets the needs of older adults in China. The population is rapidly aging, while the number of available family caregivers is decreasing as a result of the one-child policy and increasing mobility among young people (Feng, Liu, Guan, & Mor, 2012; Wong & Leung, 2012; Zhang, Guo, & Zheng, 2012). These factors have created a demand for formal LTC services, including community-based services and residential facilities (Ministry of Civil Affairs of the People's Republic of China, 2016a, 2016b), serving individuals 60 years and older (Zhan, Luo, & Chen, 2012). The number of beds in residential care facilities has been increasing in the last decade (Ministry of Civil Affairs of the People's Republic of China, 2016) and the institutionalization rate increased from 0.5% to 0.8% between the interval of 2002-2005 and 2008-2011 (Peng & Wu, 2015). While the sudden growth of these facilities represents an attempt to meet the needs of older adults in China, there has been little regulatory oversight or research into the kind of care residents are receiving (Feng et al., 2011; Wong & Leung, 2012). Thus, empirical knowledge is needed to inform the growth and development of this sector and ensure quality of care.

The limited existing literature on LTC facilities in China indicates that care quality may be suboptimal due to a number of system-level barriers, including a lack of regulations (Feng et al., 2012), insufficient funding (Feng et al., 2011), a poor staff-to-resident ratio (Feng et al., 2011), and lack of staff training (Feng et al., 2012; Hao et al., 2012). Research on LTC policy development in China has indicated that national regulations are sketchy on quality standards, staff training and credentials, and scope of services (Feng et al., 2011; Wu et al., 2009). Limited research has focused on residents' experiences with physical function in residential LTC even though this knowledge is essential to inform high-quality care (Kolanowski, Van Haitsma, Penrod, Hill, & Yevchak, 2015). Of the limited research that focused on individual-level residents' experiences with living in Chinese LTC facilities, one study explored those in four LTC facilities in Shanghai (Wang, Wang, Cao, Jia, & Wu, 2016). However, this study largely focused on instrumental activities of daily living (IADL), rather than residents' experiences with activities of daily living (ADL). Also, residents' experiences might differ in LTC facilities across geographic areas in China. Studies have reported large variations across geographic areas in terms of developmental stages of LTC facilities (Feng et al., 2011; Shum et al., 2015; Song, Anderson, Corazzini, & Wu, 2014; Wu & Caro, 2009a), as well as different levels of enactment of the limited national policy that govern this section (B. Wu et al., 2009). Shanghai, as one of the most developed cities, has been reported to lead LTC development in China, with higher levels of staff training (Wu & Caro, 2009a; Wu et al., 2009) and better implementation of available regulations on standards of care (Wu et al., 2009). Residents' socioeconomic status might differ in Shanghai and other areas in China, with Shanghainese having the highest per capita income in China (National Bureau of Statistics of China, 2016). In addition, socioeconomic status might also influence attitudes of residents and their family towards LTC facility placement (Chen, 2011),

which could potentially influence residents' experiences with living in these facilities. For residents who live in LTC facilities in less developed areas, their experiences might differ from those residents in Shanghai. Thus, research is necessary to explore residents' experiences with living in LTC facilities in less developed areas.

Strategies for meeting the rapidly growing demand for formal LTC services in China are still being developed, making this study timely. Findings may inform future research and have an impact on industry development. To that end, this study asked: What are residents' self-described challenges with daily life related to ADL and IADL in LTC facilities?

### **3.1.1 Theoretical Framework**

We employed the Adaptive Leadership Framework to guide this study (Heifetz, 1994). This framework, when applied in a healthcare context, supports the idea that individuals work in collaboration with their caregivers to achieve optimal functioning (Bailey et al., 2012). There are five key concepts: technical challenges, technical work, adaptive challenges, adaptive work, and adaptive leadership.

*Technical challenges* are situations in which both the problem and the potential solution can be clearly defined (Anderson et al., 2015; Corazzini et al., 2014). In contrast, *adaptive challenges* occur in situations where there are no straightforward solutions for the problem, and the person who has the challenge must cope with loss, change his or her behavior, or develop new skills. Challenges often include both technical and adaptive elements. An example of a challenge might be that residents are unhappy with a mealtime experience. The technical component of this challenge might be the low quality of food (Wu et al., 2012) or an unsatisfying physical environment (Divert et al., 2015). The adaptive component might be that residents miss interacting with their families as they did when they ate at home (Reimer & Keller, 2009).

Facility administrators may choose to address such challenges by improving the quality and variety of food and modifying the physical environment (*technical work*) (Divert et al., 2015). Residents might need to change their expectations and establish new patterns of social interaction during mealtime (*adaptive work*). Facility staff also may undertake adaptive work by creating opportunities for residents to interact during mealtimes and supporting residents as they interact with other residents (*adaptive leadership*).

The Adaptive Leadership Framework provides a useful lens through which to focus not solely on the limitations of the facility and residents' functional abilities, but on how to identify and enhance opportunities for residents to work with formal and informal caregivers to meet their needs (Bailey et al., 2012; Thygeson, Morrissey, & Ulstad, 2010).

## **3.2 Methods**

### **3.2.1 Overview of the Study Design**

This qualitative pilot study used semi-structured open-ended interviews (Bernard & Ryan, 2010) to explore residents' challenges with daily life.

### **3.2.2 Chinese Versions of Evaluation to Sign Consent, Consent Form, and Interview Guide**

The modified Evaluation to Sign Consent (ESC) (Items 1 and 2 out of the 5 items of the full ESC) is a measure of residents' ability to communicate and provide informed consent (Resnick et al., 2007). The two items address the potential risks of participating in the study and outline what is expected from participants, and are most applicable to this qualitative interview study. Also, these two items "have the largest percentage of agreement with the full ESC" (Resnick et al., 2007). The consent form and interview guide were developed in English by the research design team, then translated by the first author from English to Chinese. To ensure the accuracy of the translation, another qualified person back-translated the Chinese version into

English (Cha, Kim, & Erlen, 2007), and the back-translated version was then compared with the original English items by two native speakers (KNC and RAA) (Choi, Kushner, Mill, & Lai, 2012).

### **3.2.3 Sampling Procedures and Subjects**

This study was conducted in Jinan, China, which is the capital of Shandong province in Eastern China. There were 63 LTC facilities with a total of 6,556 beds in Jinan at the end of 2009, according to the most recent data available (Wu et al., 2012). Given the rapid development of LTC facilities in China (Ministry of Civil Affairs of the People's Republic of China, 2016), the number of facilities and beds had increased considerably by 2013, when this study was conducted. This study was conducted in 2013 in two, 200-bed LTC facilities in Jinan. One was government owned and the other was privately owned.

Potential participants 1) were 60 years or older; 2) could understand Mandarin; and 3) had lived in the current facility for at least a month. Purposive stratified sampling was used to recruit participants, using dependent, semi-dependent, and independent levels of mobility as strata to maximize variation (Kane et al., 2003). The first author asked facility staff members to identify residents at each of the three levels of mobility whom they thought would be able to complete the study. Residents were excluded if they had: 1) difficulty understanding Mandarin; 2) dysphasia; 3) severe deafness not improved with hearing aids; and/or 4) a visual deficit not improved with glasses. Participants were further screened using the Chinese version of the modified ESC. Residents who could not pass the ESC were excluded.

### **3.2.4 Ethical Considerations**

Institutional Review Board (IRB) approval was obtained from Duke University Health System and Shandong University. Informed consent was obtained from each of the six eligible residents who expressed interest in this study.

### **3.2.5 Data Collection and Preparation**

At each facility, the first author reviewed each participant's medical records and recorded demographic data by hand, including age, gender, level of physical function, admission date, marital status, number of living children, and education level. This information was later entered into the REDCap (Harris et al., 2009) electronic data capture tool hosted at Duke University.

Semi-structured interviews were conducted using the Chinese version of the interview guide. The first author began with, "What has been the impact of living in this facility on your life?" followed by prompts that encouraged participants to reflect on their feelings and experiences. Participants were then asked four key questions: 1) "In your daily life, what is easy for you?" 2) "In your daily life, what is difficult for you?"; 3) "Tell me about a time when staff or family members helped you with things you do each day, such as eating or dressing" 4) "Tell me about a time when you wanted help from staff or family members but it was not available." We drew on the Adaptive Leadership Framework to develop the interview questions. Each question was followed by prompts based on the Katz Index of Independence in ADL: bathing, dressing, toileting, transferring, continence and feeding (Katz, Downs, Cash, & Grotz, 1970). For example, a prompt might be, "You mentioned you need help with dressing, tell me more about that." Those residents who were independent with ADL were prompted, as well, with two context-appropriate domains of the Lawton IADL scale: managing medication and using the telephone (Graf, 2008).

All interviews were digitally recorded and conducted in the location preferred by each participant (usually their own rooms). The first author also took field notes. Interviews lasted

approximately 50 minutes each, with a range of 20 to 80 minutes. Recordings were transcribed verbatim, then proofed (McLellan, MacQueen, & Neidig, 2003) before they were translated into English. To ensure the accuracy of the translation, a second individual back-translated 10% of each transcript from English into Chinese (Chen & Boore, 2010). The back-translated Chinese versions were then compared with the original Chinese transcripts (Santos, Black, & Sandelowski, 2014). All the English transcripts were uploaded into QSR NVivo 10 for qualitative data analysis.

### **3.2.6. Data Analysis**

The team (YS, RAA, KNC, and KS) conducted data analyses using directed content analysis (Hsieh & Shannon, 2005). This approach was adopted because it allowed interpretation of data by drawing on existing theoretical frameworks (Phelan & McCormack, 2016). We used a two-cycle coding approach (Saldaña, 2012). Each transcript was read several times to gain a full understanding. For first-cycle coding, codes were applied and the rationale for coding was annotated. A priori codes were derived from the Adaptive Leadership Framework, the Katz Index of ADL, and the Lawton IADL Scale (Bailey et al., 2012; Corazzini et al., 2014). However, for any data not captured by these codes, additional codes were developed during the first-cycle coding process; these codes included quality of sleep, staff care, family care, sense of control, and overall level of satisfaction with the facility (See Table 2).



Table 2

*Example Codes from Two-Cycle Coding*

A priori codes	Codes that emerged from first-cycle coding	Second-cycle codes: example strings of dramaturgical codes
The Adaptive Leadership Framework: Technical challenge, adaptive challenge, technical work, adaptive work, and adaptive leadership ADL: bathing, dressing, toileting, transferring, continence and feeding	Psychological wellbeing: anxiety, stress, distress, and hopelessness  Staff care: staff help, staff helped but resident did not want the help, and staff did not help	R1: OBJ being able to transfer as far as needed > CON pain in legs and knees >TAT self-developed pain management strategies & TAT help from R2  R3: OBJ resident tried to manage her medications on her own > CON resident had difficulties with taking medication due to visual impairment > TAT resident relied on nurse aide to help refill medications, and look for dropped pills on the ground > ATT resident did not trust an affiliated doctor for the quality of insulin injection services that he provided > TAT resident insisted on taking insulin injections by herself and developed strategies to take insulin by herself
Context-appropriate domains of IADL: managing medication and using telephone	Family care: family help, family helped but resident did not want the help, and family did not help	R5: OBJ resident wants to transfer independently > CON staff told resident about potential consequences of transferring with wheelchair by herself & resident might interpret it as them discouraging her to go around > EMO resident did not feel comfortable proactively asking for help > ATT next time the resident might still go outside by herself without telling staff
ADL: dressing, toileting, and mobility The Adaptive Leadership Framework: Technical challenge, adaptive challenge, technical work, and adaptive work	Physical environment and quality of sleep	R4: CON resident has difficulty with mobility & CON resident has difficulty with dressing & CON missing physical care from staff with toileting > EMO resident concerned about difficulty with toileting at night > TAT resident had clothes on all the time so the toileting process could be easier (resident resilience) & TAT resident limited water intake so as to limit frequency of toileting (resident resilience) > CON resident has low quality of sleep due to having clothes on at night (New challenge emerged which might lead to long-term health consequences)

*Note.* ADL=activities of daily living, ATT=attitude, CON=conflict, EMO=emotion, IADL=instrumental activities of daily living, OBJ=objective, and TAT=tactics.

All data excerpts that were coded as both “challenge” and “ADL” or “IADL” or “psychological wellbeing” were retrieved using the query function of NVivo. For each excerpt with these co-occurring codes, we developed an analytic memo synthesizing the challenge. Then,

for second-cycle coding, dramaturgical codes were applied to the analytic memos (Saldaña, 2012). Dramaturgical coding identifies as many as six elements in each challenge: objective, conflict, tactics, emotion, attitude, and subtext. This second cycle of coding illuminated the chain of action for each challenge (see Table 2). We referred to the original quotations within the full transcripts whenever context was needed. Finally, based on the dramaturgical codes, a summary of each resident's challenge was written and patterns across and differences among residents were identified. Throughout the two-cycle coding process, we made notes that clarified coding decisions and used memos to develop ideas about explanations and themes.

Qualitative rigor was assured through a) confirmability from the team about coding and interpretation; b) dependability, using an audit trail; and c) credibility, through explicit search for disconfirming evidence (Guba, 1981; Krefting, 1991).

### ***3.3 Results***

#### **3.3.1 Resident Characteristics**

Table 3 presents participants' demographics. Four were female and widowed. The only male was married and shared a room with his wife. Participants' number of children ranged from zero to five. All strata of physical function were represented: three ambulatory residents (independent), one who consistently used a wheelchair (semi-dependent), and one who remained in bed (dependent). Participants had lived in the facility from 14 months to 13 years.

Table 3

*Residents' Demographic Characteristics*

Variable	N (%)
Gender	
Male	1 (20)
Female	4 (80)
Years of education	
0-9	4 (80)
10-12	1 (20)
Marital status	
Married	1 (20)
Widowed	4 (80)
Number of living children	
0	1 (20)
1-4	3 (60)
5	1 (20)
Gross level of physical function	
Independent	3 (60)
Semi-dependent	1 (20)
Dependent	1 (20)
Years of stay in current facility	
0-3	3 (60)
4-12	1 (20)
13	1 (20)
Variable	Mean (SD)
Age	82.6 (3.4)

### **3.3.2 Resident Challenges with Living in Facility in the Domains of ADL, IADL, and Psychological Wellbeing**

All residents described facing challenges in the domains of ADL, IADL, and/or psychological wellbeing. These challenges had adaptive and technical elements. Resident 3 was an ambulatory 82-year-old female with three children. She had been living in the government-owned facility for about 13 years. Due to visual impairment, she was unable to see the dosage measurement on her insulin injection pen. A doctor from an affiliated clinic came to the residential facility to give insulin injections every day, but she refused the service because she did not trust the doctor. As she stated, "He comes late... So I take the injections by myself. I could

take injections on time.” This resident managed to adjust the injection pen to the right dosage by counting the sound.

Resident 3’s poor vision was a technical challenge; distrust of the insulin injection service posed an adaptive challenge. Although she was able to take insulin injections independently, the safety of this practice was questionable. Her concerns about the quality of the insulin injection service were left unaddressed.

Resident 5 was an 81-year-old female with five children. She had a physical disability that prevented her from walking independently. Her family members bought a wheelchair for her and had her moved from the third to the first floor. However, she still had mobility issues. As she stated, “I can’t go beyond the door... Why would I want to bother the staff? I don’t even go to the hall now.” Although staff insisted that Resident 5 should ask frontline workers for help getting her wheelchair through the doorway, she thought they were too busy and felt uncomfortable asking them for help. Also, there were no bells or other alerts to facilitate her request for help.

Difficulties with accessing physical facilities posed a technical challenge for Resident 5; discomfort about asking for help was an adaptive challenge. To address Resident 5’s challenge, family members and the staff had provided technical solutions—a wheelchair and a first-floor room. Although mobility improved, the problem was not completely resolved.

### **3.3.3 Overall Themes Related to Residents’ Challenges**

Five themes that related to challenges emerged: staff care, care from family members, physical environment, co-residents in the facility, and resident-developed strategies.

Frontline workers engaged in efforts to address residents’ challenges, but their efforts were often inadequate. Incompetent care could even introduce new challenges for residents. Several participants relied on frontline workers to assist with daily activities, such as assistance

with medication administration and personal hygiene, but gave mixed reviews. For example, Residents 3 and 5 reported that they were able to wash their faces and feet when staff helped with the water. But staff care was inadequate for other challenges. Resident 4, who could not leave her bed without assistance, stated that “I don’t know what the yard looks like yet. Since I came here, I have never been outside. [Even if] I want to go outside, who will go with me? She [referring to one of her roommates] has a wheelchair, but who goes with me?” Also, three residents reported chronic pain in their legs or arms, but none of them reported receiving pain management from staff.

Incompetent staff care could create new challenges for residents. For example, Resident 4 was not able to dress herself because of rheumatoid arthritis in her arms. When frontline workers helped dress/undress her to assist her with other ADL, such as hygiene, they often hurt her because they did not know how to manage someone with arthritis. As Resident 4 stated, “The arm hurts when taking off these clothes. The arm can’t extend [because of] rheumatoid arthritis.”

Families provided different types and quantities of support, but residents expected more. Families provided different types and amounts of support, including physical care, financial support, and monitoring the quality of staff care. For example, Residents 3 and 5 stated that their daughters came to bathe them regularly because bathing was not provided by frontline workers. When Resident 5 was dissatisfied with the quality of care by a specific nurse aide, her daughter requested that her mother be moved to another floor. As Resident 5 stated, “My youngest daughter is thoughtful about everything, and I don’t need anything else.”

However, many residents expected more support from family members. Resident 4, who was widowed and had no living children, complained that she did not receive adequate visits or help with bathing, transferring, and cleaning her space from her daughter-in-law and

granddaughter. As she stated, “My granddaughter... has not been here for more than a month. [She is like this although] my stuff was all given to her... My clothes are very dirty...After class, [my granddaughter] could just wash these for me. Who is going to wash for me? It’s like a doghouse.” Resident 2 was an 86-year-old married male, who was independent and had one living child who was adopted. He and his wife shared a room and had been living in the privately owned facility for more than five years. His daughter provided financial support, but she rarely visited or called on the telephone. As he stated, “Look at [residents] like me, isn’t it the same [as those] who don’t have children? See, [my daughter] comes every half a year, every half a year.”

The physical environment could be a facilitator of, or a barrier to, independent functioning. Supportive physical environments helped facilitate residents’ adaptive work. For example, Resident 3, who was ambulatory and lived on the first floor, stated that, “Even now I don’t need others’ help [to go upstairs], I’m able to go upstairs [by myself]...There are handrails.” On the other hand, unsupportive physical environments could become barriers to residents’ adaptive work. Resident 5, who used a wheelchair, described the problem with a door entry barrier which prevented her from leaving her room independently, “I like to do everything by myself. The only thing I could not do is that I could not go to the bathroom”

Residents helped residents address challenges, but they generated new ones as well. Resident 1 had been living in the privately owned facility for about 14 months. She relied on Resident 2 for assistance with adapting to her emotional distress and physical pain. As Resident 1 stated, “I would always look for [Resident 2] whenever I need help.” However, help from other residents was sometimes discouraged by staff. Resident 5 once asked another resident for help with moving her wheelchair but was stopped by staff. ““Don’t let him help you,’ [the staff] said,

‘what if he does any harm to you when he helps you?’ So I don’t dare to let him help to push me.”

Residents were resilient in managing their challenges, but some strategies were maladaptive. Residents made use of their functional abilities and developed strategies to manage challenges. For example, Resident 1 found a way to manage a mobility issue independently, stating that, “[My legs and knees] would not hurt so badly if I move around after standing up. I have to move around after standing up.”

Although residents were resilient in managing challenges, their strategies could be maladaptive, in terms of the outcome. Some residents developed strategies that addressed one challenge, but created new ones. For example, Resident 4, who was bedridden, usually kept her clothes on all the time in response to her challenge with dressing due to physical limitations. But wearing the same clothes compromised other needs such as the need for a clean physical environment and good quality of sleep. Also, Resident 4 managed to go to the toilet by herself using a bedside commode. However, to avoid the hassle of getting up to use the toilet, she limited her water intake, which might have long-term health consequences. As she stated, “I’m afraid to get up [to urinate] at night...Isn’t it troublesome to get up? I drink half a cup of water, and wait until the next morning to [urinate].”

### ***3.4 Discussion***

This pilot study examined residents’ self-described challenges with daily life in Chinese LTC facilities. The Adaptive Leadership Framework guided this study design, data analysis, and interpretation of resident challenges with ADL, IADL, and psychological wellbeing. Even those participants who staff identified as having relatively high physical function, had significant unmet needs. This discrepancy implied that more accurate functional assessment is needed. We also

found that these unmet needs were consistent with evidence on the significant roles of staff, family members, physical environment, co-residents, and residents themselves in meeting residents' care needs (Brandburg, Symes, Mastel-Smith, Hersch, & Walsh, 2013; Casey, Low, Jeon, & Brodaty, 2015; Chong, 2012; Lee, 2010). To address these unmet needs, we propose that more technical and adaptive work is required by both staff and residents. For example, to avoid causing pain, staff must be better trained. Also, administrators and staff could use adaptive leadership to support residents. For example, residents who do not feel comfortable asking for assistance can be encouraged to reframe their perceptions and learn to ask for help.

Consistent with prior research (Song et al., 2014), this study found that frontline workers provided most direct care to residents at the two study sites. Many Chinese LTC facilities, even in developed areas, do not have nurses or physicians (Feng et al., 2011). Care provided by frontline workers may comprise personal care, basic medical care, room cleaning, meals, and/or laundry (Qiukui Hao et al., 2012; Wu et al., 2012). National level regulations mandate that frontline workers should provide care at levels that correspond to residents' functional levels, ranging from totally independent to totally dependent in daily life (Wu et al., 2009).

However, this study also found that frontline workers' care was often inadequate and sometimes incompetent; incompetent care induced new challenges for residents. This finding is believed to relate to consistent limitations in the training that frontline workers receive about how to provide LTC, while the requirements for staff training and certification vary in different geographical regions of China (Feng et al., 2012; Wu et al., 2012). Only a very small proportion of frontline workers have received any training compared with the large demand for frontline workers in Chinese LTC facilities (Shum et al., 2015). Where training is provided, research suggests that it is mostly delivered by more experienced frontline workers and does not follow



standardized training plans (Wu et al., 2012). This study provided empirical evidence that suggests a need for improved, comprehensive training to equip staff with the competencies to provide high-quality care.

Family members also did a lot of technical and adaptive work to address residents' care needs. For example, residents largely depended on family members to help with bathing because the care was not provided in these two facilities in Jinan. However, a study of Shanghai LTC facilities reported that assistance with bathing was provided by frontline workers (Wang, Wang, Cao, Jia, & Wu, 2016). This suggests variation of LTC services between these two areas (Shum et al., 2015; Song et al., 2014) and implies that nationwide regulations on scope of services are needed to ensure adequate and high-quality care.

### **3.4.1 Implications for Practice**

Findings from this study demonstrate the significance of the facility environment (namely, staff care and physical environment) in encouraging or inhibiting high quality of care for residents in Chinese LTC facilities. These residents-described components of the care and environment were the same with those measured by the Person-centered Care Assessment Tool that has been validated in both Western and Chinese LTC facilities (Edvardsson, Fetherstonhaugh, Nay, & Gibson, 2010; Zhong & Lou, 2013). Example items of the English version of this tool are: Item 10 “We have to get the work done before we can worry about a homelike environment” (staff); Item 12 “It is hard for residents in this facility to find their way around” (physical environment). This study provides a starting point to modify facility environment to improve quality of care in Chinese LTC facilities.

As China continues to develop its LTC system, this study has highlighted important opportunities to improve quality of care through modifying the facility environment. Improved,

comprehensive training is needed to equip frontline workers with the competencies to provide high-quality care. This need has also been well documented by previous research. Staff training level has been reported as a modifiable feature that could influence their uptake of best practices to achieve optimal quality of care (Estabrooks et al., 2015; Estabrooks, Squires, Cummings, Birdsell, & Norton, 2009; Estabrooks, Squires, Hayduk, Cummings, & Norton, 2011). Another modifiable feature that this study highlighted is the enactment and implementation of quality of care regulations and a systematic quality monitoring system. Evaluating care quality and providing feedback are important components of achieving optimal quality of care (Estabrooks et al., 2009; Hoben et al., 2017).

### **3.4.2 Implications for Research**

Results from this study reveal important foci for future research into Chinese LTC facilities. For example, in order to obtain a more complete picture of residents' care needs, observational studies are needed, in addition to perspectives of residents, family members, and staff regarding their experiences in these facilities. Also, studies are needed to explore modifiable characteristics of LTC facility environment that might have an impact on care quality, such as the roles of administrators, staff interaction patterns, and facility safety culture (Estabrooks et al., 2011). In addition, research is needed to develop quality indicators that are applicable to the local context of these facilities.

### **3.4.3 Limitations**

This study had two limitations. First, the recruitment process might have introduced bias as staff may have suggested residents they thought would not be critical of the facility. However, our findings included both positive and negative comments from residents. Further, residents described a variety of challenges with ADL and IADL. Second, we excluded those who did not

pass the ESC screening. In doing so, we most likely excluded residents with dementia, who may face particular challenges. Despite these limitations, the findings from this pilot study can inform the development of future research that could include observational data of challenges for residents with dementia.

## **4. Resident Challenges with Pain and Functional Limitations in Chinese Residential Care Facilities: a Mixed Methods Study**

### ***4.1 Introduction***

The demand for formal long-term care (LTC) is high and rapidly increasing in China (Zhang, Guo, & Zheng, 2012). LTC options in China include community-based services and residential care facilities (Ministry of Civil Affairs of the People's Republic of China, 2016a, 2016b). While the number of residential care facilities and the total number of beds provided by these facilities is increasing (Ministry of Civil Affairs of the People's Republic of China, 2016a), the quality of care is not; there is no systematic quality control (Shum, Lou, He, Chen, & Wang, 2015), and staff training and credentials are inadequate (Song, Anderson, Corazzini, & Wu, 2014). Best practices demand a resident-centered, individualized approach to care, but that is also lacking. Preliminary research identified multiple challenges that residents faced with pain and physical function in Chinese residential care facilities (Song, Scales, Anderson, Wu, & Corazzini, in press), but further research is needed to guide the development of care strategies that will enable residential care facilities to provide high-quality care to residents with pain and/or functional limitations.

### ***4.2 Background***

Evidence has suggested residents in Chinese residential care facilities might have substantial care needs in pain and functional limitations. Globally, the pain prevalence reported by LTC residents is high; in a systematic review of nursing homes, 23% to 80% of residents reported pain and a majority of these reported pain were chronic (Takai, et al., 2010). Song et al. (2014), a systematic literature review, reported the high prevalence of chronic conditions among residents of residential care facilities in China. For example, the prevalence of osteoarthritis was 40% (Hao et al., 2012). Such chronic conditions create the need to treat a resident for burdensome

symptoms, including pain and functional limitations. Also, my preliminary study identified a number of residents' unmet needs related to functional limitations (Song et al., in press). The available evidence suggests research to explore residents' care needs related to pain and functional limitations in Chinese residential care facilities.

Pain has substantial impact on the daily life of persons living with pain. Pain itself leads to suffering (Chapman, 1999). Also, studies have established the consequences of pain on various aspects of residents' daily lives in residential care facilities. Pain is associated with decreased physical function (Patel et al., 2013), a higher prevalence of depression and anxiety (Kroenke et al., 2011), impaired cognitive function (Attal et al., 2014; Moriarty, McGuire, & Finn, 2011), loneliness and social isolation (Mort & Philip, 2014), and even suicide (Hooley, Franklin, & Nock, 2014). A qualitative study on residents' experiences of pain found that pain sometimes leads to immobility, and residents in pain need more time to perform daily activities (Gran, Festvåg, & Landmark, 2010).

Pain and functional limitations are inter-related. Functional limitations often co-occur with chronic pain (Patel et al., 2013). Also, management of chronic pain is often targeted to maintaining maximal functioning while relieving pain to an endurable level (American Medical Directors Association, 2012; Lazaridou & Edwards, 2016). Thus, when studying challenges and management of pain among LTC residents, it is important to study pain and functional limitations together.

Various pain management approaches have been adopted by health care providers. These strategies include traditional western medicine (Knopp-Sihota, Patel, & Estabrooks, 2016), complementary therapies that are used in conjunction with traditional pain medicine (Houzé, El-Khatib, & Arbour, 2017), alternative therapies in place of traditional pain medicine, and

psychological interventions (Adachi, et al., 2014). Guidelines are available that direct healthcare providers how to approach pain management. For example, the American Medical Directors Association (AMDA) published the guideline for “pain management in the long-term care setting”; steps are listed regarding how to approach comprehensive pain assessment and management (American Medical Directors Association, 2012).

In response to pain, residents commonly adopt self-management strategies, where they engage in behaviors that are targeted to managing pain and functional limitations (Lorig, & Holman, 2003). For example, some older adults cut back on activities to avoid exacerbating their pain (Mackichan 2013). Because self-management of chronic conditions is inevitable (Bodenheimer, Lorig, Holman, & Grumbach, 2002), a collaborative model for chronic conditions management has been encouraged. The key element of this model is the partnership between health care providers and persons with chronic conditions (Bodenheimer, Lorig, Holman, & Grumbach, 2002).

Meanwhile, adequate management of pain and functional limitations relies on factors at various levels, including resident, staff, residing facility, and the larger health system. For example, resident-staff interaction influenced pain reporting of residents to staff and approaching staff for help (Gammons & Caswell, 2014; Gran et al., 2010). Thus, it is important to understand factors that influence management of pain in Chinese residential care facilities, to identify opportunities for improving care for pain and functional limitations.

This study was guided by the Adaptive Leadership Framework (Heifetz, 2009). When applied to management of chronic illness, this framework focuses on helping individuals to engage in problem-solving in collaboration with formal and informal caregivers to understand and address challenges that require behavior change (Anderson et al, 2015; Bailey et al., 2012)

The Adaptive Leadership Framework differentiates problems that could be defined as having straightforward solutions (*technical challenges*) from problems that do not have readily available solutions and require innovative thinking to come up with solutions (*adaptive challenges*) (Corazzini et al., 2014) and the solutions require change in behaviors or attitudes (Anderson et al., 2015). The framework facilitates strategies needed for each type of challenge (*technical work* and *adaptive work*) and identifies gaps in leadership that need to be bridged to facilitate solutions (Corazzini et al., 2014). This framework proved helpful in earlier research exploring resident challenges in daily life in residential care facilities in China (Song et al., in press). This framework highlights the complexity of residents' challenges, helps to make hypothesis regarding facilitating residents' self-management with support at staff and facility levels. Also, to address residents' challenges, this framework directs intervention development that involve collaborative work of residents and staff. Given the usefulness of this framework, I adopted it in the current study to explore residents' care needs related to pain and functional limitations in the same setting.

Using the Adaptive Leadership Framework (Corazzini et al., 2014), I explored the following aims:

**Aim 1:** Describe residents' self-reported pain characteristics and physical function (quantitative strand).

**Aim 2:** Describe, from residents' perspectives, challenges with pain and functional limitations, residents' self-management strategies, and frontline workers' strategies to manage these challenges (qualitative strand).

**Aim 3:** Describe, from residents' perspectives, challenges with pain and functional limitations, residents' self-management strategies, and frontline workers' strategies for residents at different functional levels and pain characteristics (mixed aim).

### ***4.3 Methods***

#### **4.3.1 Overview of the Study Design**

This study used a mixed-method design with quantitative and qualitative strands of data collection (Creswell, 2011). For the quantitative strand, I conducted an assessment of residents' pain and functional status with established measures (Saliba & Buchanan, 2012). This was followed by the qualitative strand of semi-structured, open-ended interviews with residents (Bernard & Ryan, 2009) to explore their challenges with pain and functional limitations. Exploring residents' challenges using both objective measures and qualitative interviews provided a more complete picture of residents' care needs in Chinese residential care facilities.

#### **4.3.2 The Facilities and Subjects**

These data were collected in 2016 in two conveniently selected residential care facilities in China, a government-owned facility in Jinan, Shandong Province and a privately owned facility in Wuhan, Hubei Province. They are the capital cities of their provinces and representative of economically advanced cities in eastern and central China. By the end of 2015, there were 167 residential care facilities in Jinan (Jinan City Bureau of Civil Affairs, 2017) and 286 in Wuhan (The Government of Wuhan, 2017).

To begin the study, I was introduced to the two facility administrators by collaborators at local universities and met with the two facility administrators to explain the purpose of the research and what would be involved, and to ask for their participation. During these visits to the facilities, the administrators gave researchers facility-level characteristics and identified a staff



member (who is a caregiver supervisor in Facility A and a frontline worker in Facility B) to be the researchers' main point of contact. The point person introduced researchers to other staff members and the residents during the subsequent recruitment process.

Observation during site visits provided information on the physical environment of both facilities. Both facilities were three-story U-shape buildings. There was a dining room with neatly aligned tables and chairs in Facility A. Residents rarely had any activities in this room except that some residents regularly had meals there. In contrast, there was a large activity room in Facility B, where some residents had meals. During non-meal time, a regular group of residents watched television and played mahjong there.

Characteristics of each of the two facilities are presented in Table 5. Facility A was a government-owned facility that housed about 100 residents. There were eleven frontline workers, no nurses, and one doctor on a contract. The doctor under contract was paid to visit the facility at regular times of the day and was responsible ONLY for giving insulin injections to residents. There were no other healthcare professionals in Facility A.

Table 5

<i>Facility Characteristics</i>		
	Facility A	Facility B
Ownership	Government-owned	Privately-owned
Number of beds	140	73
Number of residents	110	50
Number of healthcare providers (doctors and nurses)	One doctor on contract	0
Number of frontline workers	11	6
Number of resident participants	14	7

By contrast, Facility B was a privately owned facility with about 50 residents. There were six frontline workers, no nurses, doctors, or other healthcare providers in Facility B.

The national standards of care mandated that residential care facilities provide both health care and personal care for residents (Ministry of Civil Affairs of the People's Republic of China, 2013). However, during site visits, I found that both facilities were responsible for meeting residents' care needs with activities of daily living. Basic services by both facilities include delivering food, refilling hot water, and cleaning rooms. Other services were considered extra and were provided on the basis of payment level. And how much a resident paid to the facility corresponded to facility-defined dependence level of each residents. Residents were expected to obtain health care from outside of the facilities. Residents and their families were responsible for taking care of this. Outside of both facilities, there was either a community health center or a district-level hospital, as well as pharmacy stores on the same street.

In both facilities, frontline workers were expected to provide routine care which was mostly help with basic care needs. Depending on the dependency level of their assigned residents,

their range of services includes delivering food, refilling hot water, and cleaning rooms, feeding, assisting with toileting, and giving insulin injections. Frontline workers in Facility A worked on a 24-hour shift, and those in Facility B worked on day and night shifts. There were three care supervisors in Facility A, with one on each floor. In addition to providing direct care, they might also take charge of showing visitors around and introducing the facility to potential customers, who were often family members of potential residents. There was only one care supervisor in Facility B. In addition to direct care, she was also responsible for signing contracts with family members and dealing with payment when the administrator was absent.

Other staff in Facility A included kitchen staff, gatekeepers, accountants, a maintenance worker, and the administrator. Other staff in Facility B included a chef and the administrator. The administrator at Facility A was a government official with rank. Before this role, he did not have experience with working in LTC. The administrator in Facility B started her career in LTC as a frontline worker.

Criteria for resident inclusion in the study were: 1) 60 years or older, 2) could understand Mandarin, and 3) had lived in the facility for at least one month (Song et al., in press). Purposive stratified sampling was used to recruit participants, using dependent, semi-dependent, and independent levels of function, as defined by each facility, as strata to maximize variation (Kane et al., 2003). I asked facility point persons to identify residents at each of the three levels of function and to recommend subjects they thought would be able to complete the study. I then reviewed medical records of each potential resident. Residents were excluded if they had: 1) difficulty understanding Mandarin, 2) dysphasia, and/or 3) severe deafness not improved with hearing aids. Eligible participants were screened for the presence of pain by asking the question, “Have you had pain or hurting at any time in the past five days?” Screening for the presence of

pain was conducted because the assessment of pain was not a routine task in these two facilities. Potential participants were further screened using the Chinese version of the ESC. Residents who did not pass the ESC were excluded because they may not have understood what it meant to participate in the research.

Twenty-three residents were approached and all 23 passed the screening for ESC and presence of pain. Twenty-two consented to participate in this study. The other resident was not interested. Of these 22 residents who provided consent, 21 completed the study and one refused to continue after consenting. The demographics of the 21 residents who completed the study are summarized in Table 6. Of these 21 residents, five were male and 19 were widowed. Ages ranged from 65 to 91, with an average age of 83. Years of education ranged from 0 to 12. Participants' numbers of living children ranged from 0 to 7, with most having one to four children. They had lived in the facility for three months to 15 years. The strata of physical function were represented by 12 independent, 7 semi-independent, and 2 dependent residents. Residents' living arrangements before moving to the facility included staying in another facility (n=9), living alone (n=4) or with family (n=7), or being hospitalized (n=1).

Table 6

*Residents' Demographic Characteristics (n=21)*

Variable	N (%)
Gender	
Male	5 (24)
Female	16 (76)
Years of education	
0-5	9 (43)
6-9	8 (38)
10-12	4 (19)
Marital status	
Married	2 (10)
Widowed	19 (90)
Number of living children	
0	2 (10)
1-4	18 (86)
7	1 (5)
Living arrangements before moving into current facility	
Living alone	4 (19)
Co-residence with family (children or spouse)	7 (33)
Another facility	9 (43)
Hospital	1 (5)
Gross level of physical function, defined by facility	
Independent	12 (57)
Semi-dependent	7 (33)
Dependent	2 (10)
Years of stay in current facility	
0-3	13 (62)
4-8	7 (33)
15	1 (5)
Variable	Mean (SD)
Age	83 (6)

**4.3.3 Screening Tool and Measures**

I summarized the screening tool and measures used in this study in Table 7.

Table 7

*Concepts and Measures*

Variables and definition	Type of data	Source of information	Descriptions/Measures
Capacity of providing consent	Screening tool	Interview with potential resident participants	Evaluation to Sign Consent scale: 1) list two potential risks of participating in the study, 2) outline what is expected of participants, 3) describe what to do if participants do not want to continue, 4) describe what to do if participants experience discomfort, and 5) describe how participants are selected to participate in the study. Inter-rater reliability was 0.81 among nursing home residents in the U.S. (Resnick et al., 2007).
Resident demographics: personal and social information	Quantitative	Interview with residents	Age in years, gender, highest year of formal education completed, marital status (whether married, widowed, never married, or divorced), number of living children, length of stay in months in the current facility, gross level of physical function defined by each facility.
Functional status: abilities to perform daily activities independently	Quantitative	Interview with residents	MDS 3.0 scale of functional status: Bed mobility, transfer, walk in room, locomotion on unit, locomotion off unit, dressing, eating, toilet use, and personal hygiene (Saliba & Buchanan, 2012).
Pain characteristics: frequency, effect on function, and intensity	Quantitative	Interview with residents	MDS 3.0 pain scale: frequency, effect on function, and intensity (Saliba & Buchanan, 2012). Scale: <ul style="list-style-type: none"> <li>• Frequency: four-point Likert scale.</li> <li>• Effect on function: four-point Likert scale; drawn from the Geriatric Pain Assessment (Ferrell, Stein, &amp; Beck, 2000)</li> <li>• Intensity: <ul style="list-style-type: none"> <li>○ Numeric Rating Scale: 11-point Likert scale from no pain to worst pain and is widely used in long-term care settings. Internal consistency: 0.85-0.89; test-retest reliability 0.57-0.83 (Ellen, 2012).</li> <li>○ Verbal Descriptor Scale: four-point Likert scale including mild, moderate, severe, and unbearable pain. It is widely used in long-term care settings (Ellen, 2012).</li> </ul> </li> </ul> <p>During MDS 3.0 national testing among residents who reported having pain, the inter-rater reliability was 0.96 (Saliba &amp; Buchanan, 2012).</p>
Resident challenges with	Qualitative	Interview with	Interview questions: 1) Tell me about your experience with pain in daily life in this facility; 2) What has

pain and functional limitations, self-management strategies, and frontline workers' strategies		residents	<p>been the influence of pain on what you do every day, such as sleep or day-to-day activities? 3) When you have pain, what do you do with it?</p> <p>Example probes: 1) What is your experience with pain before moving to this facility? Think about sleep, what influences does your pain have on this activity? 2) You mentioned the influence of pain on.... tell me about a time when care aides helped you with these activities, such as eating or dressing?</p>
	Quantitative	Interview with residents	<p>MDS 3.0 Pain Assessment Interview: use of pain medication (Saliba &amp; Buchanan, 2012).</p> <p>Scale: Yes/no questions. Method of administration: this is originally administered by having interviewer "review the medical record and interview staff and direct caregivers" (Saliba &amp; Buchanan, 2012). However, I found that medical records were missing that record residents' day-to-day care. Therefore, interviews with residents were conducted.</p> <p>Reliability: During MDS 3.0 national testing among residents who reported having pain, the inter-rater reliability was 0.88-0.97 (Saliba &amp; Buchanan, 2012).</p>

I used the Evaluation to Sign Consent (ESC) scale to screen whether the individual met the criteria for capacity to participate and consent. ESC is a measure of a subject's ability to communicate and provide informed consent, with satisfying reliability and validity in U.S. studies. The inter-rater reliability of ESC was 0.81 among a sample of 346 residents in residential care facilities in the United States (Resnick et al., 2007). The scale asks potential participants to, 1) list two potential risks of participating in the study, 2) outline what is expected of participants, 3) describe what to do if participants do not want to continue, 4) describe what to do if participants experience discomfort, and 5) describe how participants are selected to participate in the study. The consent form and interview guide were developed in English by the research team.

I used Minimum Dataset Set (MDS) 3.0 scales of pain and functional status to assess residents' pain characteristics and physical function (Saliba & Buchanan, 2012). These scales were implemented in nursing homes in the US in 2010. They were selected in this study because they provide initial screening of pain and functional status, which was important to this study. To my knowledge, these scales had not been validated among Chinese older adults. The tools were translated by YS from English to Chinese. To ensure accuracy, the Chinese version was then translated back into English by a native Chinese speaker (Yongli Wen, a visiting scholar at Duke) (Cha, Kim, & Erlen, 2007). The back-translated version was then compared with the original version by KC, a native English speaker (Choi, Kushner, Mill, & Lai, 2012). This process is the gold standard for cross-culture research (Chen & Boore, 2010), and has been used successfully by this research team in previous work (Song et al., in press).

I conducted semi-structured interviews to explore resident-described challenges with pain and functional limitations, self-management strategies, and frontline workers' strategies. Using the Chinese version of the interview guide, I began with, "Tell me about your experience living in



this facility.” followed by prompts that encouraged participants to reflect on their feelings and experiences. Participants were then asked three key questions: 1) “You mentioned to me that you have pain. What has been your experience of living with pain in this facility?” 2) “When you have pain, what do you do to manage it?” 3) “What has been the influence of pain on what you do every day, such as dressing or moving around?” I drew on the Adaptive Leadership Framework to develop the interview questions. Each question was followed by prompts based on the MDS 3.0 scales of pain and functional status (Saliba & Buchanan, 2012). For example, a prompt might be, “You mentioned the influence of pain on your ability to move around. When that happened, how did other people help you with this activity?”

#### **4.3.4 Ethical Considerations**

Institutional Review Board (IRB) approval was obtained from Duke University Health System and Shandong University. Informed consent was obtained from each of the 22 eligible residents who expressed interest in the study.

#### **4.3.5 Data Collection and Preparation**

**Quantitative strand.** At each facility, I interviewed resident participants for demographic data, pain characteristics and functional status. These quantitative data were recorded by hand and later entered into the REDCap electronic data capture tool hosted at Duke University (Harris et al., 2009).

**Qualitative strand.** I conducted qualitative interviews with each resident participant for their descriptions of challenges with pain and functional limitations and management strategies to address these challenges. All interviews were digitally recorded and conducted in the location preferred by each resident (usually their own rooms and sometimes in the hallway, courtyard, or activity room). I also took field notes to describe the environment, interruptions or other

information that might affect the interview (Emerson, Fretz, & Shaw, 2011). Interviews lasted approximately 60 minutes, with a range of 30 to 145 minutes.

Three graduate students and I, who are bilingual in English and Mandarin, transcribed the audio recordings in Chinese, then translated them into English. Recordings were transcribed verbatim in Chinese, then proofed (McLellan, MacQueen, & Neidig, 2003). A second team member verified the transcription by listening to the recordings and comparing them to the transcripts before they were translated into English. To ensure the accuracy of each translation, a third team member verified the translation by comparing the translated version in English with the original Chinese version. All the English transcripts were uploaded into QSR NVivo 10 qualitative data analysis software.

#### **4.3.6 Data Analysis**

I completed descriptive statistics on the survey data. Microsoft Excel software (2013) was used to support the analysis.

To analyze the qualitative data, the analysis team (YS and KC) adopted directed content analysis because it allowed drawing upon existing conceptual frameworks (Hsieh, 2005). A two-cycle coding approach was used with first-level descriptive coding and second-level focused coding (Saldaña, 2012). Each transcript was read several times to gain a full understanding. First-cycle codes were applied, and the rationale for coding was annotated. These a priori codes were derived from the pain and functional status assessment scales that were used in the quantitative strand. For any data not captured by these codes, additional codes were developed during the first-cycle coding process. These codes included non-medication pain management, psychological wellbeing, and preferred outcomes by residents. (See Table 7 for examples of first-level codes).

Table 8

*Pain-related Codes from First-Cycle Coding*

Parent code	Child code	Source of code
Pain characteristics	Frequency, intensity	A priori
	Location	Emerged from data
Pain management	Medication	A priori
	Non-medication: heat, assistive device, physical surroundings, religious belief, and rest TCM: herbal medicine, <i>Guasha</i> , massage, and acupuncture	Emerged from data
Pain outcomes	Sleep, physical function, psychological wellbeing, outcomes for care aides, and preferred outcomes by residents	A priori Emerged from data

*Notes.* MDS=Minimum Data Set, TCM=Traditional Chinese Medicine.

Then for second-cycle coding, the analysis team used focused coding (Saldaña, 2012) by highlighting each data excerpt that was coded with any pain code (origin of pain, pain characteristics, pain communication, pain management, and pain outcomes). We coded these excerpts using key concepts from the Adaptive Leadership Framework (Anderson et al., 2015; Corazzini et al., 2014). Based on the Adaptive Leadership codes, a memo was written for each resident, which described challenges, residents’ self-management strategies, and pain management strategies that residents described were used by frontline workers. We further characterized these memos to address *technical work adaptive work*, and *adaptive leadership*, and missed opportunities for *adaptive leadership*, if any, within the context of each scenario. After the within-case analysis, we analyzed across all residents by identifying patterns and differences in management of pain and related functional limitations. Themes emerged in this process such as barriers to pain management and assistance for functional limitations. We moved between the quotes and the full original transcripts whenever more context was needed to interpret the meaning of the quote.

The analysis team used different strategies to establish qualitative rigor (Guba, 1981; Krefting, 1991). Regarding confirmability, the analysis team discussed codes and finalized the codebook during first-level coding. YS coded all of the documents, and KC verified the coding by reviewing the coding of half of the transcripts. KC and YS discussed discrepancies and reached an agreement with coding. To ensure dependability, we tracked decision-making of coding with memos. To ensure credibility, we conducted an explicit search for disconfirming evidence. To enhance transferability, we provided thick descriptions of the context of the two residential care facilities, how care was organized, and residents' care needs with pain and functional limitations.

To integrate quantitative and qualitative data, I used a matrix of pain characteristics, as measured by the MDS 3.0 scales of pain, and facility-defined functional levels, followed by pain locations and functional limitations as well as examples of management strategies (Creswell, 2011, p. 224). To identify patterns, I sorted by pain characteristics and facility-defined functional levels .

#### ***4.4 Results***

##### **Aim 1: Describe residents' self-reported pain characteristics and physical function (Quantitative Strand).**

I summarized in Table 8 quantitative data on pain characteristics and functional status. About half of the residents reported moderate or severe pain and the other half reported mild pain. One third of the residents reported occasional pain and the other two thirds reported almost constant or frequent pain. All the three residents with severe pain reported it to be frequent (n=1) or almost constant (n=2). An overwhelming majority reported that pain had some impact on their daily activities (n=19). To manage pain, six residents took pain medication when they felt the need.

Table 9

*Residents' Pain Characteristics and Functional Status*

Variable	N (%)
Pain intensity	
Mild	11 (52)
Moderate	7 (33)
Severe	3 (14)
Pain frequency	
Occasionally	7 (33)
Frequently	4 (19)
Almost constantly	10 (48)
Pain on daily activities	
Yes	19 (90)
No	2 (10)
Pain on sleep	
Yes	14 (67)
No	7 (33)
Use of pain medication	
Yes	6 (29)
No	15 (71)
Functional Status	
Performing ADL without assistive devices or staff assistance	10 (48)
Performing ADL with assistive devices without staff assistance	10 (48)
Performing ADL staff assistance	1 (5)

*Notes.* ADL=activities of daily living

In terms of physical function, 10 out of the 21 residents reported performing ADL without assistive devices or staff assistance; 10 reported performing ADL with assistive devices but without staff assistance. The other one resident reported receiving staff assistance with performing ADL. This resident stayed in bed for most of the time and relied on extensive assistance with dressing, eating, and transferring to and from the bed.

**Aim 2: Describe, from residents' perspectives, challenges with pain and functional limitations and residents' self-management strategies, and frontline workers' strategies to manage these challenges (qualitative strand).**

In the qualitative interviews, residents described multiple challenges related to living with pain and functional limitations. They also described a substantial number of self-management strategies to meet these challenges and significant barriers to implementing those strategies.

Although some residents described pain in one location, most described pain in two or more locations, mostly in legs, backs, and necks. Pain itself posed challenges to residents' life.

For example, R25 described her pain under one armpit:

I feel like some places are festering and a long thin layer of leather is growing after sleep overnight. The next day when I move it [the arm] it felt like it [the thin layer] was pulled off. It is tearing pain.

Residents with leg or back pain mostly reported decreased mobility as a result of the pain. Pain also impaired sleep, dressing, and toileting.

To address these challenges, residents engaged in a substantial number of self-management strategies. Table 9 presents residents' self-management strategies. The strategies were overwhelmingly non-medication approaches, such as the application of heat, use of assistive devices or physical surroundings (bed, wall, foldable chair, and so forth), leaning on religious beliefs, resting, and employing distractions. Only a few residents described taking pain medication when they felt the need or applying topical medicines. Some of these strategies were targeted to relieving the pain. For example, residents protected themselves from cold air and kept the pain site warm. Other strategies were aimed at overcoming functional limitations. For example, some residents supported ambulation by holding onto furniture in their surroundings. Importantly, several residents described using techniques of Traditional Chinese Medicine, including herbal medicine, *Guasha* (which is a traditional Chinese medical treatment in which the skin is scraped to produce light bruising), massage, and acupuncture. Most of these strategies were implemented by residents themselves without involvement of staff. Residents described

only a few strategies that they carried out together with frontline workers, residents' family, or co-residents, such as *Guasha*, herbal medicine, and message. In the following, I take R29 and R25 as two examples to describe the various self-management strategies that residents used to relieving pain and mitigating functional limitations then interpret the strategies in the context of the Adaptive Leadership Framework. These two residents were selected because they described a variety of self-management strategies.

Table 10

*Residents' Pain Locations, Functional Limitations, and Management Strategies*

Resident	Pain locations and functional limitations	Example strategies in response to pain and functional limitations
R7	Back pain	Massage and <i>Guasha</i> by frontline worker
R8	Leg pain	Avoiding cold air; massaging with a massager
R9	Low back pain, knee pain; Difficulty with position change	Religious belief; using walker to support ambulating; holding onto furniture
R11	Low back pain, feet pain, pressure ulcer; impaired mobility	Physical exercise by self; holding onto furniture; external application of medicine by family and co-residents
R12	Pain in leg, stayed in bed all the time	Adaptive physical surroundings by family
R13	Pain in eyes, shoulder pain, toothache; bed mobility	Warming eyes with help from staff, eye drops by self; maintain body turned to certain side; pain medication and selecting soft food
R14	Low back pain, toothache; limited mobility	Rest
R15	Leg pain; impaired mobility and fear of falls	Staff help to set up water for bathing feet
R16	Leg pain; impaired mobility and toileting	Walking cane, holding onto furniture
R17	Leg pain, neck pain; impaired mobility	Avoiding cold air, acupuncture
R18	Leg pain, low back pain; limited mobility	Religious belief, topical medication
R19	Low back pain; limited mobility	Keeping warm, using a walking cane
R20	Low back pain, pain while sitting or standing	Bedside foldable chair to support eating while lying on bed
R21	Pain on face	Wound care by frontline workers and self
R23	Feet pain; limited mobility	Bathing feet in warm water, pain medicine



R25	Neck, arm, and armpit, headache; bed mobility and dressing	Limiting movement, distraction by socializing with other residents
R26	Leg pain; limited mobility, taking showering	Figured out how to avoid pain on her own, pain medicine
R27	Anal pain and feet pain; impaired sleep	Religious belief and external application of medicine
R28	Leg pain; limited time for sitting and playing mahjong, limited ability to use stairs	Walking cane, belt to keep warm, diathermic lights
R29	Neck pain; difficulty with falling asleep	Taking hypnotics medicine and coordinating with constipation-relieving pills
R30	Leg cramps and neck pain, low back pain; impaired sleep	Exercise to relieve neck pain, massage legs

R29 was an 84-year old female with one child. She had been living in Facility B for one year. R29 had difficulty falling sleep due to neck pain while lying on the bed. So she took sleeping pill. She also took medicine for chronic constipation which can cause incontinence. She carefully coordinated the two medicines to prevent her from soiling her bedsheets. As she said,

I can't take the hypnotics medicine at the same time [as medicine for constipation]. I must take them at different times. I must take the constipation medicine once per three days as I can't hold it [bowel movement] on the fourth day.

Also, R29 had religious beliefs that supported her through illnesses although according to her, religious beliefs could not relieve her pain. She was aware of limitations of the medical resources she could get to manage pain. As she described, "Fundamentally, it has nothing to do with my illness, and there is no evidence that being a Christian can cure one's illness and relieve one's pains. It mainly enables you to trust yourself and to have a faith, but nothing more. I know that I have illnesses, but I don't have enough money to treat them. Therefore, I have to rely only on the god and to tell myself that god is blessing me when I feel better."

Through the lens of the Adaptive Leadership Framework, R29 engaged in adaptive work to manage neck pain, its impact on sleep, and constipation. She coordinated the hypnotics and

constipation medicine to prevent from soiling bedsheets (*adaptive work*). She also relied on religious beliefs to go through the suffering due to pain (*adaptive work*).

R25, a 79-year-old female with no living children, provided another example of residents' self-management strategies in response to pain and functional limitations. She had been living in Facility B for three years. R25 occasionally had pain in her neck and arms, or a headache. When she had a headache, she tried to manage the pain by distracting herself and interacting with other residents. The other residents were aware of R25's headaches and facilitated her strategy. As R25 stated,

...I did some activities with them [other residents in the facility] to divert my focus from the pain.

When she was in pain, R25 tended to go to the hospital rather than turn to frontline workers for help. When asked whether she wanted more help from them, R25 said,

No such thoughts. I think more about going to the hospital to examine what led to my pain.

Through the lens of the Adaptive Leadership Framework, R25 engaged in adaptive work and was the adaptive leader in managing her pain. When faced with a headache, she used distraction as her management strategy and participated in activities with other residents (*adaptive work*). Other residents acknowledged her pain and facilitated her adaptive work (*adaptive leadership*). In managing her headaches, there seemed to be missing help by frontline workers or at the facility level (gap in *adaptive leadership*).

Although residents were quick to identify strategies to self-manage pain and functional limitations and to maintain independence in daily activities, they faced significant barriers when implementing these strategies. Three barriers emerged from the data in relation to Aim 2: a lack

of access to health care, poor facility policies, and inadequate administration, services and staff care.

**Barrier 1: Limited health care.** Both residential care facilities provided limited health care, usually no more than giving insulin injections and medications. Frontline workers provided this care even though they were not licensed to perform these tasks. Some residents did not trust the quality of the care they received at the facilities and chose to seek treatment elsewhere, such as in hospital. Thus, residents had to rely on themselves or family for transportation. Often family members were unavailable. As R2 described,

Aren't they going to build a health clinic? It will be better if the health clinic is established. People can go there for some small issues. Sometimes when (the elderly) go to buy medicine... (they) can go on their own, but sometimes (they are) unable to walk, and so they have no choice but to ask him [family or staff] to go and buy (for them). If there is a clinic, then they can go (to see a doctor) when having some small issues, just buying some cold medicine or pain killer, medicine for a toothache, just buying something like these.

Even when a medical provider was available in the facility, he or she might refuse to provide the requested care. For example, in Facility A, R21 fell off the bed and cut his face, leaving a wound that required stitches. He approached the medical provider for wound care but said she was unwilling to help because wound care was outside the realm of her general responsibilities.

Some residents desired Traditional Chinese Medicine to manage pain, including herbal medicine, *Guasha*, acupuncture, and massage. They were generally not accessible in the facilities. Some residents applied herbal medicine to the skin that they obtained from outside sources. Only R7 described receiving *Guasha* from one frontline worker within Facility A. Before R17 moved to Facility A, she was accustomed to getting acupuncture to relieve her neck pain. However,

acupuncture was not available in the facility. When asked whether she could use acupuncture services outside of Facility A, R17 seemed reluctant to go alone, saying:

...who could go with me?!

Residents also questioned the competency of the care they received at the facilities. R7, R13, and R15 complained about the quality of insulin injections provided by the doctor under contract. R13 used the services because he was blind and was unable to do it by himself. Both R7 and R15 gave themselves the injections.

Due to the limited health care provided within facilities as well as concerns about the quality of care, residents needed to go outside of the facilities and interact with the larger healthcare system for needed health care. That posed problems in terms of transportation and accompaniment.

R19 is an example. He was 79 years old, married with three children who rarely visited him. He had lived in Facility A for two years. He suffered from uremia for which he needed dialysis three times a week. Because the facility did not provide dialysis, he went to the hospital for it, by bus and by himself. He also suffered from chronic low back pain, which made the transportation between Facility A and the hospital very challenging. R19 described how he managed taking bus to and from the hospital:

I lean on the cane, lean on the cane and walk there, to the bus stop. I wait there and when the bus comes, I get on, get on slowly. When I have low back pain, ouch. Now I'm able to hold onto (the bars on) both sides (of the bus door), I'm able to get on [the bus]...  
He used a walking cane to support ambulation. The facility and frontline workers did not

do anything to help him to and from the bus. Through the lens of the Adaptive Leadership Framework, the disconnection of care between the facility and the hospital posed a challenge for R19. There were missed opportunities at the system level to support R19's work to meet his care needs.

R11 was an 86-year-old female with one child. She had been living in Facility A for two years. She suffered from low back pain, and her daughter accompanied her to the hospital to get injections.

Besides relying on self or family members while interacting with the healthcare system outside of the facilities, residents sometimes obtained help from frontline workers. R13 was a 65-year-old male, married with one child. He had lived in Facility A for six years. He was blind, and his activities were limited to the floor he lived on. When he developed a serious toothache, one of the frontline workers went to a drugstore to get pain medication.

Some residents were reluctant to ask for the help they needed, even from family. R20 was an 85-year-old female with four children. She had lived in Facility A for about five months. She perceived that her children did not want to hear about her aches and pains.

When they come, if I say that it hurts here and there, it brings trouble to them, and they may not even want to listen to it. I don't dare to say anything.

***Barrier 2: Unsupportive facility policy, inaccessible administrators, and unavailable services.*** The facilities' policies and administrators were barriers at times to the ways in which residents sought to manage their pain and mitigate functional limitations. Policy failed residents when it was not targeted to their needs. For example, R23 had pain in her feet, relieved by bathing her feet in warm water. However, facility policy limited the daily amount of warm water available, which was provided only for drinking purposes, in order to save costs.

Another resident in the same facility, R29, described a policy that staff could only help residents wash their bed sheets once a month. She took sleeping pills and medicine for chronic constipation which can cause incontinence and put her at risk of soiling her bedsheets. If she did, she risked not having clean bedsheets because her frontline workers were not willing to do the extra work. She learned the hard way several times as she describes in this quote:

I can't take the hypnotics medicine at the same time [as medicine for constipation]. I must take them at different times. I must take the constipation medicine once per three days as I can't hold it [bowel movement] on the fourth day.

The careful coordination of the two medicines was aimed at preventing her from soiling her bedsheets. If she did, she risked not having clean bedsheets because her frontline workers were not willing to do the extra work. She learned the hard way several times as she describes in this quote:

...I begged them... many times. They have rules in terms of washing the quilt. For instance, if my quilt that was washed yesterday was dirty today, they would not wash it again today. (I) can't do it by myself, but it felt wrong to ask them to wash it for me.

R7, the resident whose frontline worker performed *Guasha* in order to relieve her back pain, said the facility's administrator became annoyed with the frontline worker for spending too much time with her. In response to how the administrator reacted, R7 stated, "What does the administrator care? Nothing... he doesn't even come downstairs [to the floor]. Many elderly don't even know him. Who is the leader, who is the boss?"

The inaccessibility of administrators posed additional challenges to residents. Administrators sometimes interfered with staff-resident interactions or were largely absent when they were needed.

R12 stayed in bed most of the time and needed assistance to get up. When his family visited, they helped him sit up and eat. But when frontline workers assisted him with eating, they left him lying almost flat in bed. He knew there were adjustable beds in the facility that would enable him to sit up while eating. He stated,

It could be pulled up by a handle so that you can have meals on the bed. Do you see the board (attached to the bed)? You can have meals on it. So the bed is quite suitable for people like me. My words don't count, however.

He and his family hesitated to approach the administrator because they were not familiar with him. Through the lens of the Adaptive Leadership Framework, the advanced bed was a technical/straightforward approach to maximizing R12's independence, but a lack of access to the administrator was a missed opportunity to address his needs.

Another missed opportunity came from R17, who had leg pain exacerbated by the cold. She was worried about unreliable heat in her room. She communicated her needs to her daughter, and she asked a frontline worker if she could switch to an empty room, where she would have guaranteed heat. A care supervisor told her that the administrator did not want to rent out this room, but did not tell her the rationale. R17 was not sure whether the supervisor talked to the administrator about her request. There was a missed opportunity for the administrator to listen to R17's concerns, and a missed opportunity to reassure R17 that she was being heard by offering her an explanation as to why the room was unavailable.

Residents also described services that helped with pain management, but were unavailable in the facilities. For example, R9, R18, and R27 perceived that religious beliefs helped them live with pain while other methods did not work. However, religious services were not provided in either facility. Pain and functional limitations posed a barrier to accessing outside religious services. For example, R18, an 82-year-old woman with two children, had leg and low back pain, and used a walker. She had been living in Facility A for four months, and could attend religious services via taxi. However, she said it was inconvenient to take the taxi with a walker.

Volunteer services were also perceived as helpful with the management of pain and functional limitations, but these services did not exist in Facility B. R30, an 84-year-old female with four children, had lived in Facility B for two years. She learned how to exercise in a

previous facility from student volunteers from a local university, and continued to do the exercises to relieve neck pain. She misses those services and the students who supplied them.

***Barrier 3: Lacking staff care in both quantity and quality.*** Care provided by frontline workers was influenced by interpersonal relationships. Some residents perceived that frontline workers were uncaring. Yet some residents accepted the care that was provided even though it did not meet their needs.

Routine care was not targeted towards managing pain and left much of the related functional limitations unaddressed. R16 had leg pain that made it hard for her to transfer to the bedside commode. When asked whether she had approached frontline workers for assistance, R16 stated,

Why would you ask them about this? They are not responsible for this. However, they sometimes also go and help. They help to bring the table [for meals], push the wheelchair in the room.

Residents generally thought staff care was lacking in both quantity and quality. Because of leg pain, R15 was afraid of falls while walking to and from the restroom. Also, she needed help with preparing water so that she could wash her feet. So R15 asked frontline workers for help, but timely help was not always available. As R15 said,

Sometimes, I rang the bell for 10 minutes and she [frontline workers] just did not respond. She does not care about it.

Residents expected more care to meet their care needs. For example, R15 summoned for help going to the toilet. The worker who responded to the call said,

‘What’s wrong?’ I was startled... I answered that I wanted to go to the restroom. ‘Just go. Why do you ask me to come here?’ she said. ‘I need your help. You need to support me. If not, I cannot make it myself,’ I said. Then she supported me to go to the bathroom. I would sit in the restroom a long time... I really cannot stand up after pooping. I will have to wait for her to come and pull me up so that I can put my pants on and walk back to my room.



Although residents complained about the quality of care by frontline workers, they did not think asking for more help was a good idea. As R26 said, “*I don’t want to increase others’ burdens.*”

After a fall and staying at home for two months, R16 came back to Facility A. Despite the pain she was in, she was able to use a bedpan by herself and she directly paid frontline workers to clean the bedpan every day. The frontline workers’ paid help was limited to scheduled, routine work (cleaning the bedpan). When asked whether frontline workers helped with managing pain, R16 stated,

Ah, how could the frontline workers help to do this stuff? Could they? Nobody cares, and they do not help.

**Aim 3: Describe, from residents’ perspectives, challenges with pain and functional limitations, residents’ self-management strategies, and frontline workers’ strategies for residents at different functional levels and pain characteristics (mixed aim).**

Table 10 presented the matrix of pain characteristics and functional status, followed by pain locations and functional limitations as well as examples of management strategies. I found that resident-described challenges with pain and functional limitations varied for residents with different levels of pain intensity and frequency and at different levels of physical function. Their management strategies also varied from passively ignoring the pain and limiting activities, to adopting a variety of self-management strategies, to proactively approaching staff for help. In the following, I use three residents (R14, R20, and R7) as exemplars to showcase the variation of residents’ challenges with different levels of pain and functional limitations, their self-management strategies, and if any, frontline workers’ strategies. These three residents were selected because interviews with them provided rich context that enabled this illustration.

Table 11

*Management strategies by pain frequency, intensity, and functional levels*

Resident	Quantitative data			Qualitative data	
	Pain frequency	Pain intensity	Facility-defined functional level	Pain locations and related functional limitations	Example strategies in response to pain and functional limitations
R11	Occasionally	Mild	Independent	Low back pain, feet pain, pressure ulcer; impaired mobility	Physical exercise by self; holding onto furniture; external application of medicine by family and co-residents
R14	Occasionally	Mild	Independent	Low back pain, toothache; limited mobility	Rest
R25	Occasionally	Mild	Semi-independent	Neck and arm pain, headache; bed mobility and dressing	Limiting movement, distraction by socializing with other residents
R28	Occasionally	Mild	Independent	Leg pain; limited time for sitting and playing mahjong, limited ability to use stairs	Walking cane, belt to keep warm, diathermic lights
R12	Occasionally	Moderate	Dependent	Pain in leg, stayed in bed all the time	Adaptive physical surroundings by family
R23	Occasionally	Moderate	Semi-independent	Feet pain; Limited mobility	Bathing feet in warm water, pain medicine
R26	Occasionally	Moderate	Independent	Leg pain; limited mobility, taking showering	Figured out how to avoid pain on her own, pain medicine
R18	Frequently	Mild	Independent	Leg pain, low back pain; limited mobility	Religious belief, topical medication
R8	Frequently	Mild	Independent	Leg pain	Avoiding cold air; Massaging with a

R13	Frequently	Moderate	Independent	Pain in eyes, shoulder pain, toothache; bed mobility	massager Warming eyes with help from staff, eye drops by self; maintain body turned to certain side; pain medication and selecting soft food
R27	Frequently	Severe	Semi-independent	Anal pain and feet pain; impaired sleep	Religious belief and external application of medicine
R9	Almost constantly	Mild	Independent	Low back pain, knee pain; Difficulty with position change	Religious belief; using walker to support ambulating; holding onto furniture
R17	Almost constantly	Mild	Semi-independent	Leg pain, neck pain;	Avoiding cold air, acupuncture
R19	Almost constantly	Mild	Independent	Low back pain; limited mobility	Keeping warm, using a walking cane
R21	Almost constantly	Mild	Independent	Pain on face	Wound care by frontline workers and self
R30	Almost constantly	Mild	Semi-independent	Leg cramps and neck pain, low back pain; impaired sleep	Exercise to relieve neck pain, massage legs
R15	Almost constantly	Moderate	Independent	Leg pain; impaired mobility and fear of falls	Staff help to set up water for bathing feet
R16	Almost constantly	Moderate	Independent	Leg pain; impaired mobility and toileting	Walking cane, holding onto furniture
R20	Almost constantly	Moderate	Dependent	Low back pain, pain while sitting or standing	Bedside foldable chair to support eating while lying on bed
R7	Almost constantly	Severe	Semi-independent	Back pain	Massage and <i>Guasha</i> by frontline worker
R29	Almost constantly	Severe	Semi-independent	Neck pain; difficulty with falling asleep	Taking hypnotics medicine and coordinating with constipation-

R14 was a 91-year old widowed female. She had three children and had lived in Facility A for eight years. She was independent as defined by Facility A. She had mild pain in her lower back that occurred occasionally. The resident insisted that her lower back pain was not a big problem. When asked about her experience with the lower back, she insisted that,

[The pain is] not a big problem, since I don't do labor work. I either lie on my bed, or I sit there. Not a big problem, I just walk a bit and sit there, do some exercise. My lower back doesn't feel good with too much exercise, it's old.

In doing so, she was managing pain by limiting her activities.

R20 was an 85-year old female with four children. She had been living in Facility A for about five months. She was dependent as defined by Facility A. She had moderate low-back pain that occurred constantly. The pain made it difficult for her to sit or stand. As a result, she mostly lied on the bed. She used a bedside commode and moved between the commode and her bed by holding onto the bed and moving slowly. During meals, she used a bedside chair to support eating, while lying on her side.

R7 was an ambulatory 85-year-old female with three children. She had been living in Facility A for about 15 years. She was semi-independent as defined by Facility A. R7 had severe and constantly-occurring pain in many locations of her body, and some of the pain had been with her for decades. As she said,

...there is not a single part of my body that is not hurting... I don't think others can understand. They basically just have low back pain, or just leg pain, but I have pain from top to bottom.

Because her back hurt most, she asked one of her frontline workers to perform *Guasha* on her back to relieve pain. The frontline worker did not know how to perform *Guasha*.

[I] taught her, and she did *Guasha* for me. At the beginning, it [the frontline worker's technique] was not fully correct, but it was OK. The procedure wouldn't break down (the

skin) anyway with the oil. She was just getting bruises a bit slower. Her strength was not applied to the appropriate locations, but gradually she was able to do it pretty well.

R7's persistent pain was a challenge for her. She advocated for herself by communicating her pain to staff and approached staff for help. The frontline worker recognized that the resident had serious pain but did not know how to perform *Guasha*. Although providing *Guasha* was not part of this frontline worker's job, she went beyond her routine care, learned the techniques of *Guasha* from R7, and performed it in order to relieve R7's pain.

#### **4.5 Discussion**

This study explored residents' perspectives on their challenges with pain and functional limitations in Chinese residential care facilities. There were three major findings from this study: 1) residents described significant care needs with pain and functional limitations, but self-reported not receiving staff assistance; 2) residents did much work to address their challenges with pain and functional limitations; and 3) residents faced multiple barriers to their work. The Adaptive Leadership Framework (Anderson et al, 2015) guided the study design, data analysis, and interpretation of residents' challenges and self-management strategies. By understanding residents' care needs in the context of this framework, defining them as challenges, and distinguishing adaptive from technical components of these challenges, I was able to understand the complexity of the challenges that residents faced. Also, by understanding residents' self-management strategies in the context of the Adaptive Leadership Framework and defining them as work, this study identified lacking components in management of pain and functional limitations. In addition, this framework proposed supporting residents to engage in problem solving in collaboration with formal and informal caregivers. This study identified gaps in supporting residents' self-management strategies from the facility environment, including lacking

staff care, unsupportive facility policies and administrators, and inaccessibility of health care. In the following, discussion of study findings was organized by these three major findings.

This study identified that residents described substantial care needs with pain and functional limitations, but these care needs were not captured by either facility-defined functional levels, or functional status measured by MDS 3.0. In qualitative interviews, residents described significant challenges with pain and functional limitations, even for those residents who facilities defined as having high independence levels. Also, assessment of pain identified that about half of the residents reported moderate or severe pain, suggesting substantial care needs. However, assessment of physical function with the MDS 3.0 scale of functional status revealed that a dominant majority of residents reported not receiving staff assistance with performing activities of daily living. These discrepancies provided insight into the need to develop valid measures that can assess residents' care needs in Chinese residential care facilities.

This study revealed that residents adopted various self-management strategies to address their challenges with pain and functional limitations. They mostly used non-medical strategies, a finding consistent with studies that explored pain management in residential care facilities in Taiwan (Takai, et al., 2010). Of the non-medical strategies, residents mostly reported the use of assistive devices such as canes, walkers, and furniture. The adequacy and safety of these devices are unclear. None of the residents reported using a wheelchair, which is common among residents in Western countries (Rushton et al., 2016). This may be a reflection of other physical barriers in Chinese residential care facilities such as door entry barriers that prevent passage of a wheelchair, as reported by prior research (Song et al., in press). The large amount of work that residents in this study engaged in to address their care needs suggests opportunities to meaningfully involve residents when developing interventions to foster adequate management of pain and functional

limitations. Interventions that entailed resident direction as a key component of the intervention showed promising results in enhancing pain assessment and management in LTC settings in other countries (Hoeffler et al., 2006; Sloane, Hoeffler, & Somboontanont, 2006, and Knight, Haslam, & Haslam, 2010).

In addition, this study indicated significant barriers to adopting self-management strategies by residents. These barriers included limited health care, unsupportive facility policy, inaccessible administrators, unavailable services, and lacking staff care in both quantity and quality. In the following, I will discuss these barriers and provide recommendations for practice, policy, and research of development of Chinese residential care facilities.

This study found that difficulty in accessing health care posed an overwhelming barrier for residents. Facility A had a physician under contract; there were no other health care professionals on staff at either facility to provide a variety of necessary health care services to residents, such as medical care, nursing care, and rehabilitation. Given the substantial care needs with pain and functional limitations that this study revealed, this barrier suggests the urgency of integrating health care into residential care. In China, the LTC system is separate from the other sectors of the health care system and they are regulated by two different government departments, the Ministry of Civil Affairs and the National Health and Family Planning Commission. The integration of health care into residential care facilities requires effective coordination of the LTC and hospital systems. In response to this need, efforts have been recently initiated to pilot testing programs that combine health care and residential care in China (Zhang, 2017).

Of note, although it is important to integrate health care into residential care, attention should be paid to avoid medicalizing care in Chinese residential care facilities. Research into residential long-term care services has established that high-quality health care is only one of the

necessary components that influence residents' overall quality of life (Hill, Kolanowski, Milone-Nuzzo, & Yevchak, 2011). Over-emphasis of health care often led to neglecting other needs of residents, such as respect, self-determination, and purposeful living (Koren, 2010; Lines, Lepore, & Wiener, 2015). Recently, various models have been implemented in Western countries to relinquish the traditional medical model of care in residential long-term care services (Brownie & Nancarrow, 2013; Shier, Khodyakov, Cohen, Zimmerman, & Saliba, 2014). While China is just developing its residential care facilities, efforts should be made to avoid the medical model of care.

This study also found that facility-level policies were not often in place and posed a barrier to residents' self-management of pain and functional limitations. This finding is consistent with research that facility-level barriers interfere with adequate pain detection and management in long-term care worldwide. For example, a lack of effective procedures for pain assessment and management prevents recognition of pain among residents and leads to much less treatment (Herman, Johnson, Ritchie, & Parmelee, 2009). This finding suggests the importance of developing facility policies that support residents' self-management strategies.

In addition, gaps were identified between residents' significant care needs and the lack of care provided by frontline workers. Residents described significant care needs with pain and functional limitations. But residents perceived staff care was lacking in both quantity and quality and a vast majority of the residents reported not receiving assistance from frontline workers with performing activities of daily living. This discrepancy reveals at least two possibilities. It might relate to the relatively low competency levels of these frontline workers, such as not recognizing residents' care needs with pain and functional limitations, or not having expertise to address the care needs. A systematic review of staff care in Chinese residential care facilities indicate that



frontline workers might not receive adequate training to provide competent care for residents with complex needs (Song et al., 2014). Incompetent care, whether due to the quality or quantity of assistance, can result in unaddressed pain. For example, a qualitative study of residents' experience with pain found that waiting for staff help could indirectly intensify pain (Gran et al., 2010). This suggests enhancing staff training programs to prepare frontline workers to provide high-quality care.

Also, support for frontline workers is needed to advance care for residents. Frontline workers provided most direct care in Chinese residential care facilities and, thus, are well positioned to make changes in local interactions to fulfill residents' care needs (Song et al., 2014). However, research in other countries has reported that frontline workers are often not empowered to make potential changes (Heaslip & Board, 2012; Kolanowski et al., 2015; Koren, 2010). Evidence suggests that empowerment and support for frontline workers lead to better resident outcomes (Miller, Lepore, Lima, Shield, & Tyler, 2014; Morgan & Konrad, 2008; Shier et al., 2014). This informs future development of Chinese residential care facilities to support frontline workers as they care for residents as well as facilitating residents' self-management strategies.

Another possibility of the inadequate staff care despite of residents' significant care needs might be a lack of mandated staff responsibilities related to functional limitations and pain at the facility level. Caring for functional limitations and/or pain might not be part of the care that facilities anticipated frontline workers to accomplish. So further research is warranted to explore facility-defined frontline workers' responsibilities with management of pain and functional assessment for.

In summary, the barriers that this study identified suggest how to develop residential care facilities that provide high-quality care. For example, developing infrastructures such as

establishing a resident assessment system, integrating health care into residential care, developing facility policies, and enhancing staff training, will help address residents' care needs related to pain and functional.

This study has multiple limitations. First, in both facilities, I relied on the point persons (both are frontline workers) to recommend potential resident participants. I was then introduced to each participant by the point person. So it might be possible that they only recommended residents they thought would not be critical of their facilities. However, our findings included both positive and negative comments from this sample of residents.

Second, I used ESC to screen for residents who were able to provide consent. So residents who were not able to communicate well, including those with dementia, were excluded. Individuals with dementia are vulnerable due to impaired abilities to report pain. However, findings from this study will inform the development of pain detection and management interventions for all, including individuals with dementia.

Third, this study used the MDS 3.0 scale to assess pain, and it did not involve identifying underlying causes of pain and comorbidities, which is an integral part of comprehensive pain assessment that informs pain management. As a result, we were not able to know the appropriateness of residents' self-management strategies. Also, it was unknown to what extent the barriers to residents' self-management strategies posed challenges for residents. However, residents described their self-management strategies as helpful for relieving pain and improving functional limitations.

Finally, this study did not collect data on facility-defined roles of frontline workers with pain management. Therefore, we were not able to know whether the lack of pain care resulted from staff factors or lack of mandated staff responsibilities at the facility level.

#### ***4.6 Conclusions***

Residents in the two residential care facilities in China faced significant challenges while living with pain and functional limitations. To address these challenges, they adopted various self-management strategies and faced barriers when implementing these strategies. The two facilities in this study are not representatives of the full range of Chinese residential care facilities, for which there is much variation across regions. Nevertheless, this study highlighted opportunities to facilitate LTC residents' participation in their care, to strengthen the health care team, and to develop and improve policy. Through the description of the setting of the facilities, there is an opportunity to consider the potential transferability to other residential care facilities in China.

The urgency of establishing standardized measures for resident outcomes was noted in both research and recent regulatory guidelines (Ministry of Civil Affairs of the People's Republic of China, 2017; Shum et al., 2015). These guidelines noted that the psychometric properties of measurement instruments need to be tested in the context of Chinese residential care facilities before they are accepted as valid instruments. I would caution fellow researchers that it is not enough to make assumptions based on studies in other countries.

Additional research is needed to explore facilitators and barriers to adequate management of pain and functional limitations. Previous studies have reported barriers at various levels of the context, such as factors at resident, staff, facility, and healthcare system levels. Measures are available for the assessment of barriers, such as the Barrier Questionnaire (Gunnarsdottir, Donovan, Serlin, Voge, & Ward, 2002). Understanding of these facilitators and barriers is necessary to identify potential opportunities for enhancing management work that meets residents' care needs.

Frontline workers could potentially play a key role in detecting pain and implementing pain management strategies in Chinese residential care facilities. So it is important to understand what they currently do to help residents in order to improve quality of pain care.

## **5. Dissertation Conclusion**

### ***5.1 Introduction***

Both available research and national-level regulations have highlighted the importance and urgency of improving the quality of care in Chinese residential care facilities (Ministry of Civil Affairs of the People's Republic of China, 2017; Shum et al., 2015). As a first step towards improving the quality of care, this dissertation aimed to explore residents' care needs related to functional limitations and pain. To achieve the proposed aims, a systematic literature review was carried out that synthesized existing literature on staff characteristic and care, residents' characteristics and care needs, and family care in Chinese residential care facilities. This systematic review provided context for further exploration of residents' challenges with daily life in these facilities. With an understanding of the contextual characteristics, two exploratory observational studies were conducted in three residential care facilities; they described residents' care needs in these facilities, focusing on residents' challenges with functional limitations and pain.

### ***5.2 Staff Characteristics and Care in Chinese Residential Care Facilities: A Systematic Literature Review***

We included in this review 45 articles from both English and Chinese databases. Findings indicated that functional levels of residents in these facilities were higher compared to nursing home residents in western countries. Findings also revealed that chronic conditions were prevalent in Chinese residential care facilities, suggesting potentially substantial care needs related to chronic conditions among residents. Also, findings revealed that frontline workers were older and had lower education levels in comparison with those in western countries. Most frontline workers in urban areas were migratory workers from the rural area. Also, Chinese

residential care facilities had few qualification standards for staff to prepare them for their roles in residential care facilities. Besides, family members played important roles in caring for residents in Chinese residential care facilities.

By synthesizing the literature on Chinese residential care facilities, this literature review revealed that very little research had been conducted that described residents' care needs in these facilities, despite the high prevalence of chronic conditions among these residents. The chronic conditions lead to burdensome symptoms, including functional limitations and pain; these burdensome symptoms decrease residents' independent functioning and increase staff care burden. These findings implied that residents might have a substantial number of care needs related to chronic conditions. Despite these needs, frontline workers in Chinese residential care facilities were poorly prepared to address such needs. So this literature review directed the foci of this dissertation to describe residents' care needs and to what extent these care needs were met or not in Chinese residential care facilities, which directed the foci of this dissertation.

Building on the contextual knowledge of Chinese residential care facilities, two observational studies were conducted in three facilities that explored residents' challenges with functional limitations and pain: 1) a qualitative observational study that explored residents' challenges with physical function (n=5) and 2) a mixed-methods observational study that explored residents' challenges with pain and functional limitations (n=21). In the following section of this chapter, I will summarize and discuss the three major findings of these two studies: (1) residents had significant care needs with functional limitations and pain, (2) residents adopted a substantial amount of strategies to address residents' care needs related to functional limitations and pain, and (3) residents faced multiple barriers that interfered with their self-management strategies.

### ***5.3 Care needs related to functional limitations and pain***

In the three residential care facilities, residents reported significant care needs with pain and functional limitations. Qualitative interviews with residents provided multiple examples of challenges that they faced in the domains of pain and functional limitations. Most residents described pain in various locations, mostly in legs, backs, and necks. Pain not only posed challenges in itself, but it also led to decreased mobility and impaired sleep, dressing, and toileting. Using quantitative measures, about half of the residents in the mixed-methods observational study reported the presence of moderate or severe pain. Two-thirds reported almost constant or frequent pain. An overwhelming majority reported that pain had some impact on their daily activities and sleep (n=19). In terms of physical function, about half the residents stated using assistive devices when they performed daily activities, but without staff assistance (n=10). The other residents performed daily activities without either assistive devices or staff assistance (n=10). Only one resident stayed in bed for most of the time and relied on extensive staff assistance with daily activities.

This dissertation identified a discrepancy between residents' physical function measured by MDS 3.0 and residents' self-described care needs. Assessment with the MDS 3.0 scale of functional status revealed that a dominant number of residents reported not receiving staff assistance with performing activities of daily living. This finding is consistent with existing literature that reported relatively high functional levels of these residents compared to those in nursing homes in Western countries (Li & Buechel, 2007; Wu et al., 2009). However, in contrast to the almost total absence of staff assistance, residents described significant care needs with functional limitations and pain. This finding was surprising because it indicated that staff assistance might be largely lacking that should be in place to address residents' care needs.

However, these results were captured by residents' self-report, and no observation of residents' performance of activities of daily living was conducted. So it is not clear whether the functional measures used to assess residents' functional levels among Chinese residential care facilities were valid.

Also, this dissertation identified a discrepancy between facility-defined functional levels and residents' described care needs. Residents outlined major challenges that they faced with functional limitations and pain in their residing facilities, even for those residents that facilities identified as having high functional levels. This discrepancy might indicate that facilities were not able to capture residents' care needs with functional limitations and pain. This finding implied that comprehensive resident assessment with valid functional assessment is necessary. The Chinese Ministry of Civil Affairs is urging the development of a standardized quality-monitoring system in residential care facilities (Ministry of Civil Affairs of the People's Republic of China, 2017). This quality-monitoring system is needed to capture residents' under-recognized care needs by facilities with a comprehensive assessment using valid measures.

Results from this study reveal important foci for future research into Chinese residential care facilities. For example, in order to obtain a complete picture of residents' care needs, observational studies are needed, in addition to perspectives of residents, family members, and staff regarding their experiences in these facilities. Research is needed to test psychometric properties of established measures when generalizing them from other countries to Chinese residential care facilities. In doing this, measures will be validated to be appropriate for use in the local context of Chinese residential care facilities.



#### ***5.4 Residents' self-management strategies to address residents' care needs related to functional limitations and pain***

Findings from the two observational studies revealed that residents in these three residential care facilities were resilient in making use of their physical functions and developed a substantial number of self-management strategies to address challenges with functional limitations and pain. Most of these self-management strategies were non-medication approaches and implemented by residents without staff involvement. Residents described applying heat to pain locations, using assistive devices, and leaning on religious beliefs. A few residents described self-management strategies such as taking medication or applying topical medicines.

However, these self-management strategies might be maladaptive, in terms of outcomes. Although residents developed these self-management strategies to address one challenge, some of them might create new challenges. For example, when residents had multiple challenges, such as difficulty with toileting and a simultaneous need for adequate water intake, efforts to decrease the frequency of toileting by drinking less water posed a challenge to adequate water intake.

Also, findings revealed that residents' self-management strategies varied by residents' levels of physical function and pain. Residents with higher functional levels and pain of lower frequency and intensity tended to adopt only a few strategies to avoid pain and maintain independent functioning. Residents with more dependent functioning and higher levels of pain intensity and frequency tended to adopt a variety of self-management strategies. Residents who experience severe pain that occurred frequently or almost constantly not only adopted various self-management strategies but also proactively approached staff for help.

Residents were able to develop a variety of self-management strategies to address their challenges with functional limitations and pain. The substantial amount of work that residents engaged in to address their care needs suggests opportunities to meaningfully involve residents

when developing interventions to foster adequate management of pain and functional limitations, especially in resource-limited settings. Interventions that entail resident direction as a key component of the intervention show promising results in enhancing pain assessment and management in LTC settings in other countries (Hoeffler et al., 2006; Sloane, Hoeffler, & Somboontanont, 2006, and Knight, Haslam, & Haslam, 2010). This finding also informs future research to deeply understand residents' self-management strategies, explore how the strategies were developed in the face with challenges, as well as to what extent these strategies addressed challenges.

### ***5.5 Facility-level factors affecting residents' challenges and self-management strategies***

Through this dissertation, I identified various factors that affected residents' challenges and their self-management strategies in response to the challenges. In adopting self-management strategies to address challenges with functional limitations and pain, residents faced significant barriers in these three residential care facilities. First, they thought staff care was lacking in both quantity and quality. Staff care was often unavailable when residents needed help. Second, facility policy and administrator were often not supportive of residents' self-management strategies. In many situations, facility policy was not in place to direct residents to identify potential resources that could have facilitated efforts to improve functioning and mitigate pain. When facility policies were in place, they could be unsupportive and interfere with residents' self-management strategies. Third, lack of access to health care within facilities posed another barrier for residents to obtain needed care. Limited health care was provided in the three included facilities. Residents often needed to go outside of the facilities and interact with the larger health care system to obtain needed health care. Finally, physical facilities in these facilities could be supportive of or barriers to residents' self-management strategies. Residents took advantage of

available physical facilities when developing and implementing strategies, such as relying on handrails to support walking. However, these facilities might interfere with residents' self-management strategies. For example, door entry barriers at the restroom stopped residents from moving their wheelchairs to and from the restroom. These barriers from the facility environment interfered with potentially effective strategies and prevented the development of additional strategies that could have achieved improved functioning and decreased pain.

As part of the efforts to meet residents' care needs, family members and other residents in the same facility also provided help to residents. Family members helped address residents' challenges by providing different types and quantities of care, but residents expected more care from family members. Residents also got help from co-residents to address challenges, but such assistance could cause new challenges. For example, residents helped others with pushing wheelchairs, but staff stopped this because of safety concerns.

Findings from this dissertation implied that the current infrastructure in these facilities was not able to meet residents' significant care needs with functional limitations and pain. Given that staff usually did not receive systematic training about how to provide care for residents, this finding might indicate that staff were not adequately prepared to provide high-quality care or support residents' self-management strategies. Facility policy might be under-developed due to lack of regulations for this sector or lack of quality indicators for these facilities. Also, because residents described significant care needs related to functional limitations and pain, they hoped for substantial health care, but adequate health care was not available at the three facilities. As China has just started to develop its LTC system since two decades ago, residential care facilities were developed to provide both personal care and health care (Ministry of Civil Affairs of the People's Republic of China, 2013). However, this regulation has not been strictly enforced (Shum

et al., 2015), which might have led to inaccessibility of the required health care in the three facilities.

These findings help elucidate what needs to change in Chinese residential care facilities to meet residents' complex care needs. Recommendations for practice and policy include: (1) implement staff training programs to prepare frontline workers to provide high-quality care that is targeted to addressing residents' care needs; (2) develop facility policy that supports residents' self-monument facilities; and (3) integrate health care into residential care; 4) Build and modify physical facilities that are targeted to residents' care needs.

These findings also inform further research. (1) Descriptive studies are needed to explore facility-defined roles for frontline workers and compare these roles with residents' care needs. (2) Exploratory research is needed to describe administrators' characteristics and how they were prepared for their roles. (3) Exploratory research is needed to gain more knowledge of residents' health care needs to inform how to integrate health care into residential care. (4) Observational research is needed to explore how physical facilities affect residents' care needs and efforts to address these needs.

### ***5.6 Usefulness of the Adaptive Leadership Framework***

The Adaptive Leadership Framework was used in this dissertation to direct the research designs; guide data analysis; and interpret residents' challenges with functional limitations and pain, self-management strategies, and barriers to these strategies. This framework distinguishes adaptive from technical components of challenges (*technical challenge* and *adaptive challenge*), defines residents' efforts to address challenges as their *adaptive work*, and proposes facilitation of residents' work with support from all levels in the facilities, including staff care (*technical work*) and facility leadership (*adaptive leadership*).

The framework helped to highlight residents' care needs, understand residents' self-management strategies to address their care needs, as well as identify gaps in staff care and facility environment. Findings from this dissertation indicate significant care needs that residents faced with functional limitations and pain. By understanding residents' care needs in the context of this framework, defining them as challenges, and distinguishing adaptive from technical components of challenges, I was able to understand the complexity of the challenges that residents faced. The complexity of these challenges was related to the context of these poorly-resourced facilities where residents' care needs were situated. This understanding provides implications for how to develop a resident assessment system to capture their care needs comprehensively. For example, this system should incorporate assessment of both technical and adaptive components of residents' challenges.

This dissertation found that residents used many self-management strategies to address care needs related to their functional limitations and pain. By understanding these strategies in the context of the framework and defining them as *work*, we identified gaps in current residential care facilities that could have facilitated residents' work, including lacking health care, unsupportive facility policies, and inadequate staff care in these facilities. We could build on this understanding to develop recommendations for future development of residential care facilities so they may achieve high-quality care.

Of these gaps, inadequate staff care could reflect a lack of technical expertise of staff or insufficient support of staff work by facilities. By applying this framework, we could think about how to support staff to enhance their technical expertise. We could also think about gaps in facility-level adaptive leadership to facilitate staff work. This dissertation also found that some frontline workers went beyond their defined roles and provided care to addressing residents' care

needs in these facilities. By understanding this finding in this framework and defining these types of additional care as frontline workers' adaptive work, we could think about how to facilitate their work by redefining their roles and enhancing their capacity in resident care.

This dissertation identified missing opportunities at the facility and LTC system-level that could have supported residents' and frontline workers' work. Consistently with the idea of adaptive leadership, there is a need for staff at all levels to facilitate residents' work in accomplishing their care needs. This required both technical and adaptive work from staff.

### ***5.7 Limitations***

There are four major limitations of this dissertation. These limitations related to the exclusion of persons with dementia, the sampling procedures, not conducting comprehensive pain assessment, and lacking information on defined staff care.

First, we did not proactively include residents with dementia in this dissertation. For both exploratory observational studies, we used a tool, Evaluation to Sign Consent, to screen residents who could communicate well and, thus, were able to participate in qualitative interviews. In doing so, we probably excluded residents with dementia. This subgroup of residents might have unique care needs with functional limitations and pain, which might not have been captured by this dissertation. However, findings from this dissertation inform how to improve the quality of care for residents including those with cognitive impairment.

Second, the sample of residents might be skewed in this dissertation. During resident recruitment for both observational studies, we relied on staff to provide the list of potential participants. These staff, who were frontline workers or care supervisors, might tend to recommend those residents that they thought would not provide critical reviews. However, in the qualitative interviews, residents had both positive and negative reviews.

Third, in this dissertation, we used the MDS 3.0 scale of pain to capture pain characteristics and did not conduct comprehensive pain assessment. We were not always able to tell the type of pain (acute or chronic), nor did we identify underlying causes of resident-described pain, unless residents described them in the qualitative interviews. Because acute and chronic pain and pain with different causes indicate different management approaches, we were not able to tell whether residents' self-management strategies described in this dissertation were consistent with recommended approaches by pain management guidelines. So it was not clear whether residents' self-management strategies were adaptive or maladaptive, in terms of the outcome of pain management. This implies that further research should integrate comprehensive pain assessment in the exploration of these residents' pain management.

Finally, in this dissertation, we did not collect data on facility-defined roles of frontline workers related to the management of residents' functional limitations and pain. So we were not able to know whether the lack of care resulted from staff factors or lack of mandated staff responsibilities at the facility level. Future research is recommended to describe roles of frontline workers related to the management of residents' functional limitations and pain. In addition, our findings show that research to explore frontline workers' experiences with caring for residents with functional limitations and pain is warranted.

### ***5.8 Recommendations for practice and policy***

Findings from this dissertation provided important directions for future development of residential care facilities in China. The three facilities in this dissertation are not representatives of the full range of Chinese residential care facilities, for which there is much variation across regions. Nevertheless, this study highlighted opportunities to improve the quality of care, by building a resident assessment system, enhancing staff training programs, developing facility

policy and administration, integrating health care into residential care, and improving physical environments of residential care facilities. Through the description of the context of these three facilities, there is an opportunity to consider the potential transferability to other residential care facilities in China.

A resident assessment system using valid tools is needed to comprehensively capture residents' care needs with functional limitations and pain. This dissertation indicated that there was a discrepancy between resident-described care needs and facility-defined residents' functional levels. Residents described significant care needs with functional limitations and pain, which were not captured by the gross levels of function that each facility defined. As staff provided care depending on the facility-defined functional levels, this finding indicated the potentially substantial number of unaddressed care needs by staff. This provided important directions for future long-term care practice. Facilities need to conduct resident assessment using valid tools of functional limitations and pain to capture residents' care needs in these two areas comprehensively. This system builds the foundation for subsequent efforts to address residents' care needs.

Also, staff training programs need to incorporate the knowledge and management skills about functional limitations and pain. This dissertation revealed that frontline workers played roles in addressing residents' care needs. The systematic review indicated that frontline workers usually received little training on resident care; available training was usually not systematic. Qualitative interviews with the residents revealed that residents often perceived care by frontline workers as lacking in both quantity and quality in the three facilities. Given that frontline workers are currently providing a majority of direct care in Chinese residential care facilities, their competency level is key to the quality of care that residents receive. So systematic training using



standardized modules is needed to equip these staff adequately to provide high-quality care. Given the residents' significant care needs regarding functional limitations and pain that were revealed in this dissertation, staff training should incorporate assessment and management of challenges in these two areas. Also, staff training should include knowledge and skills for how to support residents' adaptive work. Through findings from the systematic review, we also learned that frontline workers were generally older, with lower educational levels, and were immigrants from rural China. So these training programs need to target to their specific learning needs.

Facility policies are needed to support residents' self-management and frontline workers' strategies in response to residents' care needs with functional limitations and pain. This dissertation revealed that facility policies posed significant barriers to residents' self-management strategies. The following suggestions may help facilities develop policies to support addressing residents' care needed related to functional limitations and pain:

- Develop facility-level policy to have administrators accessible to residents.
- Use valid tools to assess residents' care needs with functional limitations and pain.
- Develop facility-level procedures for how to approach residents who report pain by building on current guidelines for pain assessment and management.
- Create a structure to support frontline workers' efforts to address residents' care needs with functional limitations and pain, such as by defining staff roles that are consistent with residents' care needs.
- Develop quality indicators to evaluate the process and outcomes of staff care related to functional limitations and pain.

In addition, health care needs to be integrated into residential care facilities. One of the major findings of this dissertation was that inaccessibility to health care in these facilities posed a significant barrier for residents. For example, this dissertation found that no regular doctors or nurses were available in the three included facilities. However, we identified that residents had significant care needs with functional limitations and pain. Addressing these care needs requires a comprehensive assessment of these conditions which require the expertise of health care professionals. This indicates that residential care facilities need to provide the required expertise by being equipped with health care professionals, which might include doctors and nurse. Also, various care models have been implemented in Western countries to relinquish the traditional medical model of care in residential long-term care services (Brownie & Nancarrow, 2013; Shier, Khodyakov, Cohen, Zimmerman, & Saliba, 2014). Therefore, efforts should be made to avoid medicalizing care in Chinese residential care facilities.

The available national regulations for residential care facilities mandate that they provide both personal care and health care. However, findings from this dissertation revealed that this regulation was not consistently enforced in all residential care facilities. In China, the long-term care system is separate from the other sectors of the larger health care system, and they are regulated by two different government departments: the Ministry of Civil Affairs and the National Health and Family Planning Commission. This implies that long-term care policy to support the integration of health care into residential care facilities is needed, through effective coordination of the long-term care and other sectors of the health care systems.

Finally, physical environments need to be modified to accommodate to residents' care needs with functional limitations and pain. Findings from this dissertation revealed that the use of assistive devices accounts for a significant portion of residents' self-management strategies.

However, the physical facilities sometimes prevented the use of assistive devices, thus posing barriers to residents' self-management of functional limitation and pain. It is implied that residential care facilities should enhance and build physical facilities that accommodate residents' care needs.

### ***5.8 Recommendations for Research***

Results from this study reveal important foci for future research into Chinese residential care facilities. This study revealed that residents have a significant number of care needs with functional limitations and pain in the three facilities. This suggests that epidemiological research is needed to establish the prevalence of chronic conditions and burdensome symptoms in Chinese residential care facilities. Also, future research is needed to develop measures that are appropriate for use in Chinese residential care facilities.

Observational studies are needed in addition to perspectives of residents, family members, and staff regarding their experiences in these facilities. Gaining knowledge from different sources will facilitate a complete understanding of residents' care needs, which is essential for thinking about how to involve these stakeholders (residents, family, and staff) into addressing the care needs.

Studies are needed to explore factors of facility environment that might have an impact on care quality, such as the roles of administrators, staff interaction patterns, and facility safety culture. Research is also needed to establish relationships between these factors from the facility environment and resident care needs.

Further descriptive research is needed to describe characteristics of administrators, their roles in residential care facilities, and how they have been prepared for these roles. Also, this dissertation recommends that future research explores administrator-resident and administrator-

staff interactions to inform how to build an effective administrative team that supports residents' self-management strategies and staff work in these facilities.

## **Appendix A: Evaluation to Sign Consent**

Item 1: “What are two potential risks?”

Acceptable answers:

No risk; loss of confidentiality; feel uncomfortable with some questions; get tired

Item 2: “What is expected from you, the resident?”

Acceptable answers:

Sign consent form; answer questions; talk about challenges with daily life

**Appendix B: Demographic Form**

1. Age \_\_\_\_
2. Gender: \_\_\_\_male \_\_\_\_female
3. Medical diagnosis \_\_\_\_
4. Year(s) of Education \_\_\_\_
5. Marital status:  
\_\_\_\_married  
  
\_\_\_\_divorced  
  
\_\_\_\_widowed  
  
\_\_\_\_never married
6. Number of living children \_\_\_\_
7. Living arrangements before moving into current NH:  
\_\_\_\_living alone (or with spouse)  
  
\_\_\_\_co-residence with children  
  
\_\_\_\_institutions  
  
\_\_\_\_do not know
8. Length of stay in current nursing home \_\_\_\_

### Appendix C: Evaluation to Sign Consent

Questions and answers for all questions were modified to fit into the context of the current study.

Questions	Acceptable answers
What are two potential risks?	No risk; feel tired; feel uncomfortable with some questions
What is expected from you, the resident?	answer questions; talk about pain; talk about my daily life here
What if you don't want to continue?	Ask to stop
What if you experience discomfort?	Say something; ask to stop
How is it decided who participate in the study?	Facility selected; having pain

## Appendix D: MDS 3.0 Pain Scale

<b>J0100. Pain Management</b> - Complete for all residents, regardless of current pain level	
At any time in the last 5 days, has the resident:	
Enter Code <input type="checkbox"/>	<b>A. Been on a scheduled pain medication regimen?</b> 0. No 1. Yes
Enter Code <input type="checkbox"/>	<b>B. Received PRN pain medications?</b> 0. No 1. Yes
Enter Code <input type="checkbox"/>	<b>C. Received non-medication intervention for pain?</b> 0. No 1. Yes
<b>Pain Assessment Interview</b>	
<b>J0300. Pain Presence</b>	
Enter Code <input type="checkbox"/>	Ask resident: " <b>Have you had pain or hurting at any time in the last 5 days?</b> " 0. <b>No</b> → Skip to J1100, Shortness of Breath 1. <b>Yes</b> → Continue to J0400, Pain Frequency 9. <b>Unable to answer</b> → Skip to J0800, Indicators of Pain or Possible Pain
<b>J0400. Pain Frequency</b>	
Enter Code <input type="checkbox"/>	Ask resident: " <b>How much of the time have you experienced pain or hurting over the last 5 days?</b> " 1. <b>Almost constantly</b> 2. <b>Frequently</b> 3. <b>Occasionally</b> 4. <b>Rarely</b> 9. <b>Unable to answer</b>
<b>J0500. Pain Effect on Function</b>	
Enter Code <input type="checkbox"/>	<b>A.</b> Ask resident: " <b>Over the past 5 days, has pain made it hard for you to sleep at night?</b> " 0. <b>No</b> 1. <b>Yes</b> 9. <b>Unable to answer</b>
Enter Code <input type="checkbox"/>	<b>B.</b> Ask resident: " <b>Over the past 5 days, have you limited your day-to-day activities because of pain?</b> " 0. <b>No</b> 1. <b>Yes</b> 9. <b>Unable to answer</b>
<b>J0600. Pain Intensity</b> - Administer <b>ONLY ONE</b> of the following pain intensity questions (A or B)	
Enter Rating <input type="text"/>	<b>A. Numeric Rating Scale (00-10)</b> Ask resident: " <b>Please rate your worst pain over the last 5 days on a zero to ten scale, with zero being no pain and ten as the worst pain you can imagine.</b> " (Show resident 00-10 pain scale) <b>Enter two-digit response. Enter 99 if unable to answer.</b>
Enter Code <input type="checkbox"/>	<b>B. Verbal Descriptor Scale</b> Ask resident: " <b>Please rate the intensity of your worst pain over the last 5 days.</b> " (Show resident verbal scale) 1. <b>Mild</b> 2. <b>Moderate</b> 3. <b>Severe</b> 4. <b>Very severe, horrible</b> 9. <b>Unable to answer</b>



## Appendix E: MDS 3.0 Functional Status Scale

G0110. Activities of Daily Living (ADL) Assistance																									
Refer to the ADL flow chart in the RAI manual to facilitate accurate coding																									
Instructions for Rule of 3																									
<ul style="list-style-type: none"> <li>■ When an activity occurs three times at any one given level, code that level.</li> <li>■ When an activity occurs three times at multiple levels, code the most dependent, exceptions are total dependence (4), activity must require full assist every time, and activity did not occur (8), activity must not have occurred at all. Example, three times extensive assistance (3) and three times limited assistance (2), code extensive assistance (3).</li> <li>■ When an activity occurs at various levels, but not three times at any given level, apply the following:               <ul style="list-style-type: none"> <li>○ When there is a combination of full staff performance, and extensive assistance, code extensive assistance.</li> <li>○ When there is a combination of full staff performance, weight bearing assistance and/or non-weight bearing assistance code limited assistance (2).</li> </ul> </li> </ul> <p>If none of the above are met, code supervision.</p>																									
<p><b>1. ADL Self-Performance</b> Code for resident's performance over all shifts - not including setup. If the ADL activity occurred 3 or more times at various levels of assistance, code the most dependent - except for total dependence, which requires full staff performance every time</p> <p><b>Coding:</b></p> <p><u>Activity Occurred 3 or More Times</u></p> <ul style="list-style-type: none"> <li>0. <b>Independent</b> - no help or staff oversight at any time</li> <li>1. <b>Supervision</b> - oversight, encouragement or cueing</li> <li>2. <b>Limited assistance</b> - resident highly involved in activity; staff provide guided maneuvering of limbs or other non-weight-bearing assistance</li> <li>3. <b>Extensive assistance</b> - resident involved in activity, staff provide weight-bearing support</li> <li>4. <b>Total dependence</b> - full staff performance every time during entire 7-day period</li> </ul> <p><u>Activity Occurred 2 or Fewer Times</u></p> <ul style="list-style-type: none"> <li>7. <b>Activity occurred only once or twice</b> - activity did occur but only once or twice</li> <li>8. <b>Activity did not occur</b> - activity (or any part of the ADL) was not performed by resident or staff at all over the entire 7-day period</li> </ul>	<p><b>2. ADL Support Provided</b> Code for most support provided over all shifts; code regardless of resident's self-performance classification</p> <p><b>Coding:</b></p> <ul style="list-style-type: none"> <li>0. No setup or physical help from staff</li> <li>1. <b>Setup</b> help only</li> <li>2. <b>One</b> person physical assist</li> <li>3. <b>Two+</b> persons physical assist</li> <li>8. ADL activity itself <b>did not occur</b> during entire period</li> </ul>																								
	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 50%; text-align: center;">1. Self-Performance</th> <th style="width: 50%; text-align: center;">2. Support</th> </tr> </thead> <tbody> <tr> <td colspan="2" style="text-align: center;">↓ Enter Codes in Boxes ↓</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </tbody> </table>	1. Self-Performance	2. Support	↓ Enter Codes in Boxes ↓		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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<p><b>A. Bed mobility</b> - how resident moves to and from lying position, turns side to side, and positions body while in bed or alternate sleep furniture</p>																									
<p><b>B. Transfer</b> - how resident moves between surfaces including to or from: bed, chair, wheelchair, standing position (excludes to/from bath/toilet)</p>																									
<p><b>C. Walk in room</b> - how resident walks between locations in his/her room</p>																									
<p><b>D. Walk in corridor</b> - how resident walks in corridor on unit</p>																									
<p><b>E. Locomotion on unit</b> - how resident moves between locations in his/her room and adjacent corridor on same floor. If in wheelchair, self-sufficiency once in chair</p>																									
<p><b>F. Locomotion off unit</b> - how resident moves to and returns from off-unit locations (e.g., areas set aside for dining, activities or treatments). If facility has only one floor, how resident moves to and from distant areas on the floor. If in wheelchair, self-sufficiency once in chair</p>																									
<p><b>G. Dressing</b> - how resident puts on, fastens and takes off all items of clothing, including donning/removing a prosthesis or TED hose. Dressing includes putting on and changing pajamas and housedresses</p>																									
<p><b>H. Eating</b> - how resident eats and drinks, regardless of skill. Do not include eating/drinking during medication pass. Includes intake of nourishment by other means (e.g., tube feeding, total parenteral nutrition, IV fluids administered for nutrition or hydration)</p>																									
<p><b>I. Toilet use</b> - how resident uses the toilet room, commode, bedpan, or urinal; transfers on/off toilet; cleanses self after elimination; changes pad; manages ostomy or catheter; and adjusts clothes. Do not include emptying of bedpan, urinal, bedside commode, catheter bag or ostomy bag</p>																									
<p><b>J. Personal hygiene</b> - how resident maintains personal hygiene, including combing hair, brushing teeth, shaving, applying makeup, washing/drying face and hands (excludes baths and showers)</p>																									

## **Appendix F: Interview Guide (Chapter 3)**

The questions in this protocol will guide interview with participants. These questions will prompt what additional questions to ask.

### **1. Grand tour question: What has been the impact of living in this nursing home on your life?**

Probes:

- What brings you pleasure in living in this NH?
- What is the most difficult part of living in this NH?

### **2. In your daily life, what is easy for you? What is difficult?**

Probes:

- Think about bathing/dressing/toileting/transferring/continence/feeding. What is difficult?
- Can you give me an example?

### **3. Tell me about a time when staff or family members helped you with things you do each day, such as eating or dressing?**

Probes:

- Think about bathing /toileting/transferring/continence. Did you have similar experiences when you were helped with it?
- If residents indicate getting help, ask if they wanted help with that activity.
- If residents indicate not getting any help with the above domains, ask about IADL (eg. Taking medicine, combing, brushing teeth, cutting toenails and making phone calls.)
- Tell me more about that event.

### **4. Tell me about a time when you wanted help from staff or family members but it was not available.**

Probes:

- Think about bathing/dressing/toileting/transferring/continence/feeding. Did you have similar experiences when you wanted help from staff or family members but it was not available?
- Tell me more about that event.

I have finished with my questions. Do you have anything else you want to talk with me about, or tell me about today? Thank you again for your time and participation in our study.

#### **Field notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

Length of Interview:

Where did interview take place?

Describe resident's physical and/or emotional status during interview.

Describe any interruptions that occurred.

Describe any observations or reflections that I have about this interview that I feel are relevant to the analysis of this interview.

## **Appendix G: Interview Guide (Chapter 4)**

### **Warm-up:**

#### **Tell me about your experience with living in this facility.**

Probes:

- What do you like in this facility?
- What is easy for you living in this facility?
- What is the most difficult part of living in this facility?

#### **1. You mentioned to me that you have pain, tell me about your experience with pain in this facility.**

Probes:

- How do you feel about your pain?
  - How do you feel when you have pain?
  - How do you feel at other time when the pain does not happen? (If frequency of pain is not “always”)
- How long have you been feeling this way?
  - Do you manage pain in the same way or different after you moved to this facility?

#### **2. When you have pain, what do you do to manage it?**

Probes:

- What makes the pain better?
- Who helped you to manage pain?
  - a. Could you share an example of how this person generally helps you to relieve pain?
  - b. How do you feel with the help?
  - c. Is that what you want?
  - d. Specify “other people” if it is hard for the participant to come up with an example situation.
    - i. Do you have an example to share when staff/your family/your friends helped you to manage pain?

#### **3. What has been the influence of pain on what you do every day, such as dressing or moving around?**

Probes:

- Think about (ADL domains from MDS: moving around, dressing, eating, using toilet, and personal hygiene), what influences does your pain have on this activity?
- Think about sleep, what influences does your pain have on this activity?
- You mentioned the influence of pain on .... (such as dressing and moving around). In general when you have pain, how did other people help you with this activity?
  - How do you feel with the help?
  - Is that what you wanted?
  - Specify “other people” if it is hard for the participant to come up with an example situation.
    - Do you have an example when staff/your family/your friends help you with this activity when you are in pain?

- You mentioned the influence of pain on.... Do you have an example to share of when you have pain and want help from someone else to manage this activity, but the help is not available.
  - What help did you want in that situation?
  - How did you feel with it when the help was unavailable?
  - Specify “other people” if it is hard for the participant to come up with an example situation.
    - Do you have an example when you want help from staff/your family/your friends to help you with this activity but the help is not available?

I have finished with my questions. Do you have anything else you want to talk with me about, or tell me about today? Thank you again for your time and participation in our study.

**Field notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

Length of Interview:

Where did interview take place?

Describe resident’s physical and/or emotional status during interview.

Describe any interruptions that occurred.

Describe any observations or reflections that I have about this interview that I feel are relevant to the analysis of this interview.

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## **Biography**

Yuting Song was born in the city of Linyi, China, and completed her Bachelor of Science in Nursing at Shandong University, China, in 2012. Ms. Song is currently a Ph.D. student at the Duke University School of Nursing. The focus of her research is improving the quality of nursing care of older adults in long-term care, for which she is the first author on two manuscripts, “Staff Characteristics and Care in Chinese Nursing Homes: A Systematic Literature Review”, which was published in 2014 in *International Journal of Nursing Sciences* and “Resident Challenges with Daily Life in Chinese Long-term Care Facilities: A Pilot Study”, which was accepted by *Geriatric Nursing* and currently in press. Ms. Song has received funding from Duke University for her research, including the Duke Global Health Institute Doctoral Certificate Fieldwork Award, Duke Bass Connections Follow-on Student Research Grant, and research awards from the Duke University School of Nursing and Graduate School. In 2013, Ms. Song was inducted into Sigma Theta Tau International Honor Society of Nursing.