



## Debating “Good” Care

### The Challenges of Dementia Care in Shanghai, China

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#### Abstract

The increasing number of dementia sufferers in China has transformed dementia care from a private issue to a public concern. Nationwide dementia-friendly campaigns have intensified debates about what constitutes “good” care. In response to these campaigns, the Shanghai government proposes a systematic care model, which stresses the need for dementia-care units and professionalization. Non-state actors, however, focus on the relational care model, which integrates Western humanitarian ethics with Confucian values. This article employs cultural and structural frameworks to examine why and how a specific form of “good” care is constructed in China. The debates about the establishment of dementia-care units and the professionalization of eldercare enable us to understand how politics shape certain forms of care.

**Keywords:** *dementia care; state-society relations; forms of life; China; humanitarian ethics; Confucian values*

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## Debating “Good” Care

### The Challenges of Dementia Care in Shanghai, China

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During periods of rapid social transformation, contending values and moralities often take center stage. China is a rapidly changing nation, having experienced five thousand years of imperial rule; about a hundred years of foreign invasion and exploitation; decades of Maoist-socialist domination; and finally, in 1978, a “socialist market economy.” Each transition produced fears of instability and debates about traditional practices, especially as they related to Confucian values. The practice of eldercare, for a long time, was considered a domestic issue. There was no need to talk about it in public settings. Recently, this has begun to change. First, numerous studies have revealed intergenerational conflicts and eroding family practices of filial piety during rapid social change (Ikels 2004, 2006; Yan 2003b). Second, the social impact of the one-child policy and the expansion of empty-nesters in urban China are raising concerns about the adequacy of eldercare services to support family caregiving (Liu *et al.* 2015; Zhang 2006, 2009, 2017a). Lastly, while the eldercare industry is growing, it attracts public attention due to the preexisting institutional mistreatment of elders (Dong *et al.* 2008; Wang *et al.* 2018; Zhang 2017b). All of these factors lead to new debates about what constitutes “good” care for the aging population in China.

The increasing number of elders with dementia intensifies debates around “good” care. Medicalization, which unfortunately reinforces the stigma surrounding dementia in China (Ramsay 2013; Zhang 2018), transforms the care for this groups of people. Previously, dementia was considered as a sign of normal aging, and seniors with dementia symptoms were cared by their family members (Ikels 1998). Since the medicalization, services are organized in a way that people with dementia passively receive care mainly from medical institutions, which directly threatens their identity (Zhang 2018). In order to avoid stigma, domestic settings become the primary sphere for dementia sufferers. However, social services, such as nursing homes and community-based programs supporting patients and their families, are underdeveloped.

Dementia-friendly campaigns recently initiated by different stakeholders (e.g., non-governmental organization campaigners, nursing home managers, government officials, intellectuals, and social media producers) are changing the landscape of eldercare in China (Zhang, forthcoming). For a variety of reasons, advocates on behalf of dementia sufferers and their families frame their arguments about “good” care within the context of Western humanitarian ethics. They propose that elders with dementia should have equal access to institutional, community-based, and in-home care. Family caregivers, who are the primary resources for dementia sufferers, should be supported by the state and society. However, the conceptualizations of “good” dementia care and the ways to achieve it are controversial among the multiple stakeholders.

In this article, I introduce two constructions of “good” dementia care in Shanghai. On the one hand, there is the governmental construction of systematic care, which emphasizes affordability, accessibility, and efficiency. Systematic care invests in infrastructure, professionalizes services, enforces top-down governmental projects, and, often, ignores local contexts. On the other hand, non-state actors focus on the relational dimensions of care in their conceptualizations of “good” care. Barnes (2012) has theorized care as a way of conceptualizing personal and social relations in Western societies and, humanitarian care ethics for dementia sufferers is built upon this notion. In this article, I expand the concept of relational care in East Asian societies where Confucian ethics, such as *ren*, construct the practice of relational care. *Ren*, which means benevolence and humaneness, is

the fundamental human virtue that binds people together first in appropriate familial relations and then directs other social relations by the model of familial relations (Bell 2007; Confucius 1971). This overlaps with the concept proposed by Barnes. But, the difference is that relational care—with an emphasis on *ren* in China—is more about a paradigm than simply relationships between caregivers and recipients. Building on both Confucian ethics and Western humanitarian care ethics, this type of care values social inclusiveness, genuine respect and support for elders, and the family-like culture in institutions. In practice, systematic care and relational care often coexist in eldercare facilities, which can create conflicts and resistance between state and non-state actors regarding how to provide “good” care.

Based on my fieldwork, I contend that both Chinese government and non-state actors value “good” care for dementia sufferers. That is, both the state and non-state actors believe it is urgent to take actions to support elders with dementia and their families. However, due to different responsibilities and expectations, each stakeholder exhibits variations in conceptualization and practice of “good” care. I put good care in scare quotes to highlight the ongoing debates among stakeholders. I argue that debates between state and non-state actors are inextricably related to the conceptualization and practice of “good” care. In examining these debates and tensions, I pay attention to the underlying cultural and structural contexts that make each version of “good” care favorable.

Because “good” care is related to the notion of “good” life that is debated by scholars, in the following section, I bring together different conceptualizations to contextualize what is at stake in pursuing the desired life. I analyze how governmentality studies in China and global humanitarianism contribute to the debates about “good” dementia care. After discussing my research methods, I introduce the eldercare system in Shanghai to explain why the state adopts a systematic approach in dealing with dementia sufferers. After that, I introduce the moral worlds of people with dementia to highlight the stigma issues that a systematic care approach often fails to address, but a relational care framework can add value to. In the following sections, I attend to two specific debates regarding dementia care. These debates have coincided with China’s introduction of long-term care insurance, the Western humanitarian ethics, and Dementia-Friendly projects. Meanwhile, cultural practices such as the adoption of family-like culture in eldercare facilities and public discrimination against nursing aides remain important in these debates.

## Governmentality and the Good Life in China

Ethnography has documented the transformation of governmental rationality from ideological security during Maoist China to pragmatic security in capitalist China (Greenhalgh and Winckler 2005; Hua and Guo 2007; Jeffreys 2009; Zhang *et al.* 2011). As Chen (2007) argues, recent political reforms are characterized by the state making a strategic adjustment from a politics of efficiency to a politics of equity, in order to address the social issues resulting from economic development. Social issues related to the wellbeing of the population include: HIV/AIDS (Shao 2006; Uretsky 2015), environmental health (Lora-Wainwright 2017; Tilt 2010), eldercare (Farquhar and Zhang 2005; Zhang 2017), rural education (Harwood 2009; Yan 2003a), moral challenges (Kleinman *et al.* 2011; Wu 2010), and spiritual wellbeing (Cooke 2009; Gao and Qian 2019). The shift from Maoist ideology of tight population control to post-Mao governmentality indicates the changing governance of human life in China. The purpose is to push life beyond just the survival of living beings to a level of affluency and human flourishing (Zhang *et al.* 2011).

What constitutes a good life varies from context to context, from issue to issue, and from place to place. Kleinman explores the moral dimensions of human life, such as “how to live a moral life” (2006:72), “moral as an experience” (1999: 373) and “what really matters” (2006:1). Tu (1985, 1989) responds to this question from the philosophical perspective, emphasizing the differences between Western and Eastern understandings of human flourishing. Rose and Novas (2005) address this issue by employing the concept of “biological citizenship,”

which means not only the right to health, but also the duty to be well. In other words, the emphasis on the good life indicates the shift in concern from survival to human development, and from mortality to vitality. This concept is further elaborated by Zhang and colleagues (2011), who analyze the changing state-society relationship that plays a crucial role in what constitutes the good life. Anthropologists have mainly used these approaches to describe the historical and cross-cultural dynamics of good life and the obstacles to achieving it.

I shift my attention from *what* constitutes a good life to *why* and *how* a specific form of good life is constructed locally—namely, the cultural and structural contexts that make it favorable. Anthropologists have emphasized forms of life and their association with cultural norms and structural factors regarding life and death, health and illness, and care relations and personhoods (Chua 2014; Danely 2019; Lee 2019; Traphagan 2000). For instance, a specific regime of life fostered by world “disorders” and global non-governmental organizations (NGOs) is humanitarianism (Fassin 2011; Feldman 2018; Redfield 2013; Ticktin 2011), which concerns the wellbeing of life, but with particular agendas. No matter how nonpolitical humanitarian actors are, the challenges of serving older adults—such as service gap between the structure of the aid system and the demands of senior recipients—often shape how people experience their own lives (Feldman 2018).

In the face of the increasing number of dementia sufferers globally, moral concerns have provided a powerful ground for international NGOs and local governments to adopt Western humanitarian ethics in place of local policies. The Dementia-Friendly Initiatives, which advocate for equal human rights for dementia sufferers, have been advertised by Alzheimer’s Disease International globally. As a result, many nations have engaged with this project (ADI 2017). Despite its global humanitarian aspiration, local responses to this project may transform this nonpolitical project to a political one. The localization of the Dementia-Friendly projects is inevitably related to the conceptualization of good life for dementia sufferers. I argue that social reconfigurations between global humanitarian aspiration and local transformations not only shape certain forms of good life, but also create new tensions that hinder the efforts to achieve it. These new tensions, I suggest, are closely related to cultural and structural complexities.

The utility of the cultural and structural framework to understand how and why a specific form of good life is constructed in China is twofold. First, this approach encourages an examination of a specific form of good life. For example, Farquhar and Zhang (2005) introduced the neo-Confucian tradition of self-cultivation and nurturing life as an alternative approach for elders in Beijing. This form of life is characterized by a totalistic “health moralism”—a physical culture related to Maoism (e.g., strong bodies, endurance, and willpower). Second, the cultural and structural framework suggests useful debates among various constructions of good life. Initiation of a certain form of good life, for instance, has often been linked to exercises of social power. The power might come from the state, such as “authoritative paternalism” (Rose 2011), or from everyday institutions or non-state actors with aspirations, struggles, and dilemmas (Zhang 2010). Theories of governmentality have examined the manifold ways that wellbeing and social power can be entangled. For instance, a growing body of literature sheds light on the fine line between sociopolitical powers that are repressive and controlling and those that are caring, productive, and supportive (Cooper 2008; Zhan 2011; Zhang 2014). Instead of placing productive and repressive power in contrast to one another (Greenhalgh 2008; Kligman 1998), Zhang and Ong (2008) challenge the oppositional relationship between state and society and argue that these two forms of power can engage in the co-production of practice, values, and solutions. My intention in this article, however, is to examine conflicts that arise from different constructions of “good” care by state and non-state actors, even though each aims to create and promote better social services in China.

In this article, I propose to understand the debates about “good” care in China as a historically contingent formation that emerges from the continual interface between the state and society. Rather than drawing a clear line between generative power and repressive power, I trace each form of “good” care within a specific historical, cultural, and structural context, in which both the state and society aim to generate, craft, and

enhance the wellbeing of human life. The debates about “good” dementia care gives us a different perspective to examine the co-constructive relationship between the state and society, in which the state takes a benevolent role in responding to popular demands and various social groups call for this potential to advance their interests. The uncertainty, distress, and insecurity that arise from these debates also highlight the relationship among certain forms of care and politics.

## Methods

My exploration of dementia care in Shanghai, China started when I was a project manager for a local NGO between 2010 and 2013. At that time, my colleagues and I tried to introduce the Western humanitarian care model for dementia sufferers into a community called the Bund. The Bund, or Waitan Community, is located at the center of Shanghai. According to the Sixth Population Census in China, there were 64,896 people whose hukou<sup>1</sup> were registered in the Bund. The exact number of people living there was unknown because of the migrants from outside of Shanghai and people migrating out of the community. More than one third of the total population were seniors aged 60 and above in 2017 (SRCA 2017). Therefore, social services for elders are a key topic in the domain of Civil Affairs. Due to the severe stigma, however, no official social services were developed to support family caregivers for people living with dementia by 2010. Family caregivers often hid dementia sufferers from outsiders because of the associated dementia (Goffman 1963). Dementia sufferers, who were often undiagnosed and untreated, became invisible. Introducing Western humanitarian care model is a response to the limited social support for family dementia caregivers. During this project, I was able to participate in community activities and conduct interviews with various stakeholders, especially family caregivers about their daily struggles. When I started my doctoral program in the United States in 2013, I visited this community each year until 2017.

Data presented in this article were mainly collected during ethnographic research on governance and dementia care between 2014 and 2017 (20 months of fieldwork total). The months I spent in Shanghai included annual shorter visits, mostly in the summer, between 2014 and 2016, and the entire year of 2017. In addition to continuing my research in the Bund, I also visited three senior centers specialized in dementia care and five mini-nursing homes.<sup>2</sup> These facilities were located in six neighborhoods. Moreover, I conducted in-depth interviews with nine nursing home managers and four directors of NGOs about their understandings and practices of dementia care. In order to gain a comprehensive understanding of dementia care policies, I interviewed six government officials at different administrative levels. I also spoke to a wide variety of people in several neighborhoods, including family caregivers, volunteers, and eldercare service providers. I conducted archival research on aging policies and collected secondary data including publications in Chinese related to eldercare. I examined public debates on dementia care through websites, TV programs, newspapers, and the like. Lastly, I attended two national conferences, two municipal conferences, and several small-scale meetings about dementia care. These various sources of information enabled me to systematically study the Shanghai government agenda regarding dementia care and the struggles and complaints of non-state actors.

## Creating a Systematic Eldercare Model in Shanghai

Shanghai has been the “oldest” city in China since 1979 when 10.2% of the total population (about 1.16 million) was aged 60 and above. In 2017, those over the age of 60 reached 33.2% of the total population of Shanghai, with 3.18 million of these individuals above the age of 65 (SRCA 2017). There is also an increasing rate of dementia, with more than 150,000 people with dementia in Shanghai, or about 5% of elders aged 65 and above (Zhang *et al.* 1990) suffering from the disease.<sup>3</sup>

The government is primarily responsible for building systematic care that is efficient, affordable, and accessible for seniors. In practice, this systematic care model is administration-oriented and enforced from the top. Governmental efficiency is evaluated by the number of eldercare facilities, the allocation of financial resources, and the organization of social services. Consequently, local governments often pursue quantity rather than quality of services. Eldercare programs, which include nursing home care, community-based care, and in-home care, are often implemented from the perspective of service providers, instead of users.

Nursing home care is one type of eldercare services in which the Shanghai government has invested. As of 2017, there were 703 nursing homes with 140,000 million beds total (SRCA 2017). These nursing homes primarily focus on daily needs and offer basic medical care services by themselves or by outsourcing to collaborating medical institutions. There are also hospital-style nursing homes that have doctors, nurses, nursing aides, and basic equipment, such as a laboratory, CT scanners, and that for rehabilitation. By 2017, there were 39 hospital-style nursing homes in Shanghai. These two types of nursing homes are either public or private, or a hybrid of the two. Of the nine nursing homes in which I conducted fieldwork, three were public, four were private, and two were hybrids. Two of nursing homes focused on healthcare and the rest mainly provided support for daily life.

Even though nursing home care is an important social service, community-based eldercare programs have attracted the attention of seniors due to lower prices and easier access. Unlike nursing homes, which may be located far away from downtown Shanghai, these institutions are often located within the more urban neighborhoods. There are two types of community-based eldercare programs. The first is senior centers, which enroll independent elders or elders who need minor assistance. There were 560 senior centers in 2017 (SRCA 2017). The second type is mini-nursing homes. I call this type of facilities mini-nursing homes because they are small in size, with each providing between ten and 49 beds. These facilities provide respite care for family caregivers, enrolling elders with mild functional disabilities or cognitive impairment, those in need of rehabilitation services, and elders waiting for nursing-home beds. Because of its community-embedded nature, family caregivers can easily visit seniors. Because mini-nursing homes successfully combine professional services with traditional family caregiving, the Shanghai government has invested a lot to promote this type of care model since 2015. When I conducted my fieldwork in 2017, 127 mini-nursing homes were functional, and more were under construction (*ibid.*). These two types of community-based eldercare programs are typically hybrid in nature (i.e., cross between public and private). The three senior centers and five mini nursing homes I visited were run by local NGOs, with five specialized in dementia care, two for general eldercare, and one offer care that was a mix of the two.

Besides the two types of nursing homes discussed here, home eldercare is the third component of the systematic care model in Shanghai. Historically, home care was only limited to those living without relatives, independent living abilities, and financial resources. Yet, as the life expectancy and potential eldercare burden among families continues to increase, since 2018, home care has been expanded to include all seniors who meet certain criteria (discussed below). Home care for seniors includes daily support activities, such as chores and meal delivery. Some municipal eldercare programs provide regular home visits (e.g., the Senior Partner Project) and housing maintenance for elders with low incomes or living alone. These services are usually outsourced to local NGOs or other governmental organizations, depending on each community's infrastructure. These services are subsidized by the government for elders who qualify due to their economic standing.

The long-term care (LTC) project, which ensures the affordability of social eldercare services, is another significant mark in the development of dementia care in China. This project had an initial trial in Qingdao (north of Shanghai) in 2012, and later expanded to a national trial in 2017. In Shanghai, three districts were experimental sites: Xuhui, Putuo, and Jinshan. In practice, LTC was a multi-agency program: the Shanghai Municipal Human Resources and Social Security Department took charge of financing, the Shanghai Civil Affairs Bureau oversaw

the service organization, and the Shanghai Municipal Health Commission provided necessary training and evaluation. In-home care and institutional care were both provided by the LTC. These services mainly focused on daily support and basic medical care. To be eligible for LTC services, citizens have to be 60 years or above and have been evaluated at the second level of disability or above.<sup>4</sup> Three to seven hours of in-home care services were organized weekly for recipients based on their disability levels. LTC covered 90% of the cost, and individuals paid the rest. For institutionalized care, LTC covered 85% and individuals paid 15%. The pricing strategies were 45 RMB/hour [\$6.30 USD/hour] for daily life support and 85 RMB/hour [\$11.90 USD/hour] for medical care in 2017. Considering the potential benefits for older population, the Shanghai government has expanded this policy to all neighborhoods since January 2018. However, as a fundamentally new social policy in China, controversies and obstacles are not uncommon in practice.

As part of the systematic care approach, the Shanghai government aims to professionalize dementia care. Nursing homes, community-based senior centers, in-home care, and long-term care insurance are common in Western societies, but these concepts and institutions remain relatively new in China. Note that eldercare is traditionally a family-based practice, and China still mandates that family has the responsibility for eldercare (Zhang 2017a). The government's eldercare system has indeed laid the foundation for the development of additional social services, but the public is often disappointed by the quality of care provided (Dong *et al.* 2008; Wang *et al.* 2018; Zhang 2017b). Particularly, dementia sufferers were previously excluded from the preliminary care system. Therefore, to build a sustainable and systematic care system for those with dementia is both seen as an indicator of a modern society and as a sociopolitical achievement by the Chinese government.

## Moral Worlds: Stigma, Dementia, and Caregiving

Before the Dementia-Friendly Initiative, family caregivers and those with dementia inhabited moral worlds that were to a considerable degree constructed by stigma. Based on my work as a project manager in charge of dementia care services from 2010 to 2013 and my fieldwork from 2014 to 2017, I found stigma made both dementia sufferers and their family caregivers susceptible to loneliness and isolation. Strategies used to fight against stigma include denial and keeping the diagnosis secret. At times, family caregivers rejected any kind of social support. In order to schedule a family visit, I often had to turn to the neighborhood committee for help. Otherwise, it was difficult to enter into the households of those with dementia. I found when visiting patients at home, family caregivers tended to avoid the label of dementia by using courtesy terms to describe their loved ones' conditions, such as poor memory, brain atrophy, and even "too old."<sup>5</sup> Family caregivers had to care for the entire household. Often, I could see only two family members: the person with dementia and the caregiver. Other family members and friends often shied away. After several times visiting and showing my genuine understanding of their suffering, family caregivers led me into their moral worlds.

In the summer of 2016 when I did my pilot study, I stayed with two host families that had elders with dementia. Mrs. Mo's mother, aged 80, was diagnosed with dementia about two years ago. During my two-month stay with this family, a topic we consistently discussed was how to help elders with dementia since most of them refused to take medication or receive any outside support. When I talked to Mrs. Mo's mother about dementia, she often said, "I am fine. I don't have dementia. Why do you always talk to me about it?" The paradoxical form of living with dementia, but rejecting the diagnosis, has also been captured by Lee (2019). She found that due to the stigma, many people with dementia in South Korea are not told directly about their diagnosis by both physicians and their family members. In China, a diagnosis with dementia means a social deprivation of one's moral status. Therefore, the denial of dementia is a rejection of unworthiness and uselessness in later-life, which is often associated with power asymmetry between caregivers and care recipients. Even though Mrs. Mo's mother experienced cognitive decline, one thing she was consciously aware of was the conversion from a life-long caregiver to a receiver of care. When Mrs. Mo was absent, her mother often lamented, "I have taken good care of my children and grandchildren for my whole life. Now I am useless and have to

check their face to survive. No face anymore!” The medicalized notion of dementia establishes a new framework in which the relationship between one’s cognitive ability and being recognized by surrounding people enacts one’s right as a person (Taylor 2008). In China, loss of face means the loss of one’s moral status and personhood, which also indicates a loss of respect and trust that one feels one deserves.

Similarly, when I stayed with Mrs. Zhuang, who was a 70-year-old single woman, she also expressed her anxieties about potential mistreatment by others if she revealed her diagnosis:

I haven’t told my neighbors about my diagnosis because I do not want to be looked down upon. When they know that I have dementia, they will cheat me and treat me like a child. Will that be good for my illness? No! I only told some of my close friends who can understand my difficulties and are willing to help me. I do not even want to tell my two brothers in Fuzhou. They have their own family issues and they would not understand, anyway. I am also worrying about my future. I can take care of myself now. What about ten years later? What should I do to prepare? When I am thinking about these difficulties, I am too anxious to sleep.

The dehumanizing effects of the dementia label are the main reasons that most dementia sufferers refused to see doctors and/or acknowledge their diagnosis (Kaufman 2006; Lock 2013; Traphagan 2000). Family caregivers also internalize the stigma surrounding dementia. In order to avoid stigma, some family caregivers relocate their kin to other communities. When I asked a service provider about her experience of the dementia care program in the Bund, she told me that two of her visiting families moved out of the neighborhood. Family caregivers are frequently ambivalent about seeking social support due to associated stigma (Goffman 1963). On the one hand, seeking support for dementia sufferers means that someone in the family has a mental disorder that is not socially accepted. On the other hand, family caregivers are the ones who have been worn out emotionally, psychologically, and physically due to the long-term care they provide. The capacity for traditional family support is also tenuous. This is not only due to the rapid social transformation of Chinese society, in which the emphasis on the extended family has transitioned to the nuclear family (Yan 2003b), but also because of the associated stigma. During my fieldwork, I encountered family caregivers who experienced broken family ties—such as estranged siblings, divorce late in life, and unfilial children—because of the dementia-related stigma. Without effective social and family support, most family caregivers experience depression, and some even commit suicide.<sup>6</sup> An increasing number of people living with dementia transforms family dementia caregiving from a private problem to a public concern.

## Dementia Matters

Only recently has dementia care become a public issue in China. In 2010, when I started working in an NGO, my colleagues and I initiated the first project of social support for family dementia caregivers in Shanghai. Before that, no official support was provided to these caregivers, and only one municipal nursing home enrolled elders with dementia. Most nursing homes rejected these individuals because of the liability. This was not a problem exclusively in Shanghai; only a limited number of social organizations focusing on dementia care existed nationwide.<sup>7</sup> In 2017, when I started fieldwork, there had been a dramatic change. There were four NGOs specialized in dementia care and family support. Many nursing homes listed dementia care as one of their services. Organizations advocating on behalf of people with dementia and their families had sprouted everywhere in China. The rapid change in attitudes about dementia was due to the public portrayal of dementia care as an overwhelming burden on families, the increasing number of people living with dementia, as well as the increasing number of people advocating on behalf of dementia sufferers and family caregivers (Zhang, forthcoming).



State and non-state actors respond to dementia issues differently. The Dementia-Friendly Initiative, led by the Shanghai government, employs the systematic care approach. This approach deals with elders with dementia through effective management. The government views dementia sufferers as a special group of individuals whose needs can be met by building dementia-care units within existing eldercare facilities. Moreover, the state actively promotes LTC insurance to help dementia patients gain access to eldercare facilities. The Shanghai government believes that dementia care, like other social services, can be enhanced through improving the care workers' skills. Consequently, the state mandates the professionalization of dementia services in the LTC project and also introduces the project of building dementia-friendly communities to ameliorate the stigma around dementia sufferers.

At the grassroots level, non-state actors conceptualize "good" care differently. Building upon Western humanitarian ethics and Confucian ethics, non-state actors focus on improving the relational dimensions of dementia care, e.g., social inclusiveness, person-centered care, stigma reduction, and family-like institutional cultures. The integration of Western humanitarian care ethics with traditional Chinese values, such as filial piety and *ren*, attempts to improve dementia services. These key elements contribute to a new vision of "good" care—relational care—which is valuable, but yet, inadequate in China. Within this framework, non-state actors seek to strengthen the relational dimensions of human life, which have been waning during the past four decades of reform in China. The pursuit of relational care signals a massive shift from the state's administration-oriented care to one that is bottom-up and quality-oriented. This form of care highlights a new public culture with regards to dementia.

While acknowledging the co-constructive relationship between the two versions of "good" care for the professionalization of dementia services, conflicts still arise when each stakeholder operationalizes different theories of "good" care. One conflict concerns the investment of constrained resources. Should we invest in dementia-care units or family-like institutional culture when there are limited resources? Another conflict concerns service professionalization. Should eldercare institutions follow the state's rigid standards or do they have the authority to decide how to practice "good" care? Although these debates do not give an exhaustive portrayal of the features of "good" care, they demonstrate why the application of certain forms of dementia care can be read as a site of power struggle between various stakeholders with contending values.

## Investment Debates

Since the Shanghai government initiated the Dementia-Friendly project, one significant change in eldercare facilities has been the establishment of dementia-care units. According to the official standards, requirements for dementia-care units include location, space, layout, decoration, and care ratio. These elements are easy to quantify and evaluate. Once facilities meet these requirements, the Shanghai government subsidizes 10,000 RMB [\$1,400 USD] for each dementia-care bed and another 10,000 RMB [\$1,400 USD] to the general facility. While acknowledging that dementia-care units are necessary for "good" care, in practice, most facilities pay more attention to infrastructure than to services. Several factors contribute to this phenomenon. First, investing in infrastructure is much easier than investing in services. When facilities apply dementia-care models from other societies to Shanghai, they assume the most important thing is to build a physical space and configure necessary equipment to make it look like a "high-quality" dementia-care unit. Second, paying attention to infrastructure is also an easy way for eldercare facilities to benefit from the state policies. As a result, an increasing number of eldercare institutions have started to build dementia-care units in order to receive the governmental subsidies. Lastly, the appearance of eldercare facilities serves as the first impression to the public. Therefore, many nursing home managers pay attention to their infrastructure.

Among the nine nursing homes I visited, three had dementia-care units, and four were planning to create them. Yet, the rationale behind the dementia-care units was not directly related to providing better care

for seniors with dementia, but more about keeping those cognitively intact from unnecessary interruptions. Mr. Xu, who was a nursing home manager, expressed the importance of risk avoidance in managing elders with dementia:

If you place a cognitively intact senior with a dementia sufferer in one room, it will be dangerous. The X nursing home, which often had such an arrangement, had a disaster in 2005. An elder with dementia killed his roommate without any punishment. The responsibility was fallen completely on the nursing home. If your institution has such a disaster, you are doomed. From the administrative perspective, you cannot guarantee that they [dementia sufferers] will not affect other people around... Therefore, it's better to separate them from others.

Separating dementia sufferers from cognitively-intact residents also could provide an equal division of workload among nursing aides. Ms. Liu was in charge of a large nursing home that could accommodate about 400 seniors. When I visited the nursing home in 2013, they had just opened with fewer than ten seniors with dementia. In 2017, there were about 80 clients with severe dementia symptoms. With so many elders with dementia, a key strategy of management was, according to Ms. Liu, to separate them from other seniors. When I asked about their dementia-care units, she frankly told me that they had three floors hosting dementia sufferers. Each floor represented a different level of care: the higher the floor, the more intensive the care needed. A senior couple I encountered during my visit to this nursing home were both diagnosed with dementia. However, due to the intensive care needed for the husband, this couple had to stay on separate floors. This was to equally distribute workload among care providers.

The over-investment in dementia-care units and infrastructure has led to a public culture in Shanghai that evaluates the quality of care based on facilities and equipment. During my fieldwork, many cutting-edge eldercare nursing homes were established, most of which focused on wealthy citizens. These nursing homes were private, and often boasted about their high-tech instruments. Therefore, fees for service were much higher than that of average nursing homes. For average ones, monthly fees were about 5,000 - 10,000 RMB [\$700-1,400 USD] based on care levels. However, upscale nursing homes charged about 20,000 - 35,000 RMB [\$2,800- 4,900 USD] per month or even more, which was far beyond the average monthly pension (4,200 RMB or \$588 USD in 2016) in Shanghai (SRCA 2017). Many clients judge the institutional care based on equipment, instead of services. When I visited a nursing home specialized in late-stage dementia, a young man who was visiting his grandma complained about the poor infrastructure to the nursing home director. After discussing with the man that his grandma had been bedridden for 14 years without any issues in this nursing home, the director said, "If you send your grandma into a presidential suite, will your grandma get better? She cannot get better, right? It's not our infrastructure that sustains your grandma's life, but our service!" Infrastructure for nursing homes is necessary, but the over-reliance on technology could lead to a substandard care. Instead of paying attention to the infrastructure, some nursing homes focus on the link between the needs of dementia sufferers and institutional cultures, such as inclusiveness and person-centered care. These elements derive from Western humanitarian ethics, but are transformed by non-state actors during the process of localization, which includes bringing them together with Confucian values.

The first characteristic of relational care in the Chinese context is a family-like institutional culture. Inclusiveness and person-centered care are based on Western conceptions of human rights, but these norms in an institutional culture that values collectivism have a different meaning. According to nursing home directors I interviewed, dementia sufferers should be included in all activities, and should not be treated as a stigmatized group by constructing a separate dementia-care unit. Among the nursing homes I visited, two managers maintained a critical attitude toward dementia-care units. One nursing home had 70 clients in total, 32 of whom were dementia sufferers. The reason for rejecting a dementia-care unit was their commitment to building a family-like institution. Mrs. Pan, the nursing home director, said, "We are a big family, and we should mutually

support each other within this family, especially when some members are in need of more care.” When I conducted observations in this nursing home, all staff and nursing aides would call each client “grandpa” or “grandma.” This is a culturally appropriate way to shorten the distance between caregivers and patients and to show respect. Caregivers are treating their clients as family members, rather than consumers. While the market-based care undermines the motives essential to care, the appropriate combinations of market and family care (e.g., treating clients as family members) strategically solve the ethical dilemma of commercialization of care.

The second characteristic of relational-care is the expectation of involving families after their kin are institutionalized. This differs some nursing homes in the West where patients are seen as only consumers (Kane and West 2005) and from the dementia-care-unit approach in Shanghai. Based on my observations and interviews, many seniors still had the expectation of family affection, even after they were enrolled into nursing homes. “They do not want to be abandoned by their families,” said Mr. Xue, another nursing home director. From Mr. Xue’s perspective, doctors, nurses, nursing aides, and other staff helped families, rather than replacing them. At Mr. Xue’s nursing home, when he enrolled elders, he would ask families to come and visit them. He believed that, no matter how professional the services were, their goal was supporting families. In traditional Chinese culture, as in other parts of the world, parents raise their children, and when they are old, it is adult children’s responsibility to take care of their parents. Rapid modernization and the competitiveness of the job market have reduced the ability of children to devote themselves to eldercare. However, Mr. Xue stated,

Sending parents to institutions does not mean that their children’s responsibility is over...Many seniors complained that their children did not come and visit them. When I told them that their children would come, they were very happy. The happiness that children brought to their parents cannot be replaced by professional care. Thus, family love cannot be replaced; it can only be supplemented.

Nursing homes have different ways to make sure that families visit their elders. For example, some nursing homes make it a rule that adult children have to visit their parents once or twice a week to make sure that family affection is available to their clients. One nursing home I visited required families to help nursing aides bathe elders. If family members did not show up, the nursing home would call them. In some extreme cases, elders suffered from poor hygiene because adult children failed to come. Then, there would be a public discussion about these unfilial children. Other nursing homes used modern social media (e.g., WeChat) to help seniors to get in touch with their families daily or weekly. The involvement of family members in institutional care not only characterizes the Chinese version of “good” care, but also challenges the dementia-care-unit model, which often isolates elders from the community.

The last action that non-state actors promote is creating a stigma-free environment. Famous nationwide campaigns include the Yellow Bracelet Project, which aims to prevent people with dementia getting lost, and the Dementia Friends Project, which tries to redress the public stigma associated with dementia. In 2018, the Shanghai Civil Affairs Bureau responded to these campaigns by mandating that discriminatory words such as, *chidai* (dementia), *laonian jingshenbing* (senior psychosis), and *shizhizheng* (loss of wisdom), should not be used in eldercare facilities. This official statement is an attempt to destigmatize the condition. However, its effect is limited to eldercare facilities. Therefore, non-state actors appeal for more public education with the hope of changing attitudes toward dementia. Mrs. Pan stated, “We should let citizens know what dementia is, why these seniors behave in such a way, and we also need to train our children to know what we should do when we meet dementia sufferers on the street.” Changing the public attitude toward dementia not only corresponds to the essential element of social inclusion, but also casts family-like institutional care culture into the larger society. The relational care paradigm has transformed both traditional Chinese culture that stigmatizes dementia sufferers, and Western humanitarian care ethics, which may ignore local context.

In China, Confucian values such as filial piety and the ethical code, *ren*, have been successfully integrated with global practices by non-state actors. The state, which also endorses Western humanitarian care ethics, adopts the systematic care approach to deal with dementia care challenges. This approach is valuable in terms of building infrastructures, such as dementia-care units. Its limitations include not fully creating culturally-appropriate services, which generate more constraints when the state intends to professionalize how care should be practiced.

## Service Professionalization Debates

Coupled with the project of building dementia-care units is the professionalization of services. Government officials, who emphasize quality control along with the systematic care model. According to policy makers, nursing aides should receive certain course hours of training, pass the national exam, and obtain the state issued license. This enforcement often overlooks the concrete practices of eldercare and the social and economic background of nursing aides. Nursing home directors argue for relational care that takes both nursing aides and care practices into account. According to them, eldercare should be outcome oriented. The prerequisite for nursing aides is to be kind-hearted and express loving compassion, rather than being qualified enough to obtain a license. Therefore, debates about the professionalization of dementia care mainly center on the rigidity of state administration and the competency of nursing aides.

The introduction of the LTC insurance intensified the conflicts between the governmental understanding of professionalism and non-state actors' practices of "good" care. This conflict arises because the Shanghai Quality and Technique Supervision Bureau monitors the quality of care in nursing homes. Instead of checking the services provided to elders, this bureau requests that each nursing aide completes a form to record their work every day. This form is complex and nursing aides spend a great deal of time completing it. In turn, this reduces their work hours and affects the quality of services provided to elders. When I visited nursing homes, the government officials present that day checked these forms in cursory manner. Some public nursing homes hired someone to deal with the supervision; however, private nursing homes did not want to comply with governmental supervision for fear of sacrificing the quality of care provided to their clients. Therefore, many private nursing home directors complained about this rigid supervision. Mrs. Bai explained, "Filling these forms are superficial work, not only meaningless for us, but also a waste of social resources. Our government does not understand what eldercare is."

Another rigid and formalized requirement to ensure "good" care is to take pictures when delivering services. For example, a nursing aide has to take pictures when he/she feeds, moves, or changes a senior's diaper. This regulation, however, has nothing to do with "good" care; instead, it increases the workload for nursing aides. Many nursing home directors complained about this requirement. Even the public nursing home I visited, which specialized in dementia care and had a high care ratio (1:4), could not meet this requirement. Private nursing homes that often had a lower care ratio (e.g., 1:6-1:8),<sup>8</sup> felt even more frustrated. A nursing home director, Mrs. Yu stated, "I do not think our government understands how eldercare is practiced in nursing homes. If you want to see whether a senior has enough food and water, can you only tell that from pictures? Now, the officials only check pictures. Without taking pictures, they will blame us for failing to do this and that."

The policy change regarding the competency of nursing aides further complicates debates about professional care. Previously, nursing aides had to obtain either medical or eldercare licenses to enter into the workforce. These two types of licenses indicated their professional levels and authorized them to work in particular domains, and thus also determined their salaries. In order to control cost, many nursing homes preferred to hire those who held eldercare licenses instead of medical licenses. But, since the introduction of LTC, the Shanghai government requires that all nursing aides have to obtain medical licenses, which does not cut costs for nursing homes.

This change has challenged the development of social care in Shanghai. First, it increases the cost of institutional services. According to Mr. Xu, hiring a nursing aide with an eldercare license before the change cost about 7500 RMB [\$1,050 USD] per month. They now have to pay more than 10,000 RMB [\$1,400 USD] to hire a qualified nursing aide with a medical license. Second, the transition from a loose policy whereby a nursing home could hire nursing aides with or without medical care licenses to a tightly controlled policy has reduced the number of nursing aides on the job market. People might think this can be solved by raising salaries, but this challenge will not be easily solved. On the one hand, rapid population aging in Shanghai will continue due to extended life expectancy, the consequences of the One-Child policy, and the relatively low birth rate and mortality rate (SRCA 2017). On the other hand, it takes a certain period of time to improve the educational background of nursing aides. Research has showed that most nursing aides in China are from remote areas and have limited education (Chu and Chi 2008; Dong *et al.* 2017; Song *et al.* 2014). According to a survey in Shanghai, less than 5% of nursing aides had a college degree (Wang and Yuan 2018). When I did my fieldwork, almost all nursing aides in Shanghai were from rural areas and had limited education. Moreover, not all nursing aides had obtained a license to legally work in an institution. According to Mrs. Yu, “They are doing this work only because their children are in college and they have to support them.” In her institution, there were eighteen nursing aides: only two were less than fifty years old, one was sixty, and the rest were in between. All were from rural areas and three were illiterate without any licenses. I found such situations in other nursing homes too. When I interviewed nursing home directors, they told me that, because of the rigid governmental policy, those who had not passed the exam and obtained the medical care license would be laid off by the end of 2017.

The question is whether the next age cohort is able and willing to be nursing aides to make up for this shortage. The computer-based exam presents additional challenges. Although an exam is necessary to select well-trained aides, the computer-based exam requires a candidate to have computer skills. Therefore, this exam excludes many qualified nursing aides simply because of their limited knowledge of computers. This is to be expected, however, since most nursing aides are from rural areas and have limited access to computers. In Mrs. Yu’s nursing home, she and other staff had trained their nursing aides to use computers to pass the exam, nonetheless only twelve passed the exam; the other six failed. Mrs. Yu expressed her sadness, “Training for nursing aides is helpful because eldercare is practical; but a license is meaningless for us. These licenses are for administration. If illiterate nursing aides have to get licenses, I don’t think we will have enough people to do this work.” The next age cohort who were born in the 1970s or early 1980s, might not be willing to do a job that is considered as “dirty” and “unproductive” (Jervis 2001). Some of them are the only-child. With higher educational levels, they are socialized to become part of the elite. The only-child generations are viewed as being spoiled and refusing to do dirty and hard work (Fong 2006). Therefore, this policy change has created more struggles and dilemmas for the development of eldercare in China.

Public discrimination against nursing aides poses another challenge to the professionalization of eldercare. Being a nursing aide has a very low professional reputation in China (Wang and Yuan 2018). In domestic settings, skeptical family caregivers often treat nursing aides as domestic helpers, regardless of their license status. They assign nursing aides to carry out household chores, rather than providing professional care to seniors. The public, and family caregivers in particular, do not trust nursing aides because of their assumed “lower quality” (Yan 2003a). Many family caregivers that I interviewed, often doubted the professionalism of nursing aides. One family caregiver said, “These nursing aides are low-quality. They are doing this job only for money, rather than truly care about my father. When he soils the bed, it is me and my sisters who take turns caring for him. I cannot believe that a nursing aide can perform like my family.” This distrust is intensified in the case of dementia sufferers since these patients often do not like “strangers” in their homes. In such situations, most family caregivers only ask nursing aides to do household chores, rather than deal directly with their kin.

The lack of trust between nursing aides and family caregivers further challenges the state's systematic care. The LTC project, which ensures systematic care, provides more subsidies to family-based eldercare than institutional-based care. Because of the lack of trust, most family caregivers said that if they could not handle the burden of caregiving, they would send their kin into professional nursing homes rather than seeking domestic support. Because of the unpleasant interactions with family members in the home, some nursing aides prefer to work in institutions. Consequently, most family caregivers have to take on the majority of care tasks, even though the LTC project aims to provide effective social support to them. Many stakeholders have realized that a trusting relationship requires the public to respect the work of nursing aides. According to Mrs. Li, the director of a nursing school, "The further development of eldercare is not a financial investment; rather, it should be social and cultural change. If our society continues to discriminate against nursing aides, no one will join in this cause, no matter how much money we offer."

## Conclusion

This article has traced debates between two forms of "good" care for dementia sufferers in Shanghai, China. While acknowledging these debates are historically contingent in order to address the urgency of social support for elders, they equally reveal interactions between state and society—two forms of power in constructing modes of care. The relationship between these two forms is opposing yet co-constructive. In the systematic care model, the state possesses the authority to establish social policies and laws. This form of care has been implemented through the construction of dementia-care units and the professionalization of dementia care services, especially the standardized training of nursing aides. Non-state actors, especially nursing home directors, exercise their agency by embracing relational care, which integrates Western humanitarian ethics with Confucian values. Some nursing home directors have generated grassroots strategies for creating a family-like institutional culture to negotiate the state care regime. Moreover, these directors advocate for nursing aides, who are primarily from rural areas and have limited training. While acknowledging the significance of professionalization of eldercare, nursing home directors are consciously aware of the potential challenges of these rapid policy changes. Condemning public discrimination against nursing aides, non-state actors claim that "good" care cannot be achieved without taking the social rights of formal caregivers into account.

No matter how apolitical relational care seems, it mobilizes an ethical code that systematic care often ignores, which makes these two forms of care seem oppositional. Yet, in the real world, these two forces can be mutually constructive. For instance, developing culturally appropriate dementia care becomes necessary when there is already an eldercare infrastructure, and to further professionalize dementia care requires governmental guidelines and standards. The seemingly opposing relationship between state and non-state actors actually supplements each other to produce better outcomes. Systematic care should constitute the backbone of relational care—both are essential to better dementia care.

Debates highlight the uncertainty, distress, and insecurity when two forms of power interface with each other in practice. The emphasis on professionalization of services without taking the experience of nursing aides into consideration creates uncertainty as to how to develop sustainable, accessible, and affordable social eldercare. Similarly, inappropriate regulations, even with a benevolent purpose, to some extent, place additional anxieties and distresses on nursing home directors who have already been struggled with "good" care. The speed and the scale of these policy changes will continue to intensify the insecurity of institutional care. Too rigid state requirements reduce the attention nursing homes can give to their clients. Therefore, it requires both state and non-state actors to craft, adjust, and remodify these policies.

Cultural factors, such as stigma further, complicate these debates. The systematic care approach, which intends to reduce the stigma, reinforces it because dementia-care units separate dementia sufferers from others. The relational care model, however, emphasizes family-like institutional cultures, which could mitigate

dementia-related stigma. These two approaches exemplify the role of cultural elements in promoting better dementia care. In order to generate culturally appropriate programs for dementia sufferers, state and non-state actors must work together to maximize social benefits. A sociopolitical and cultural transition to a more favorable environment for elders with dementia is needed in China. These debates about “good” care serve as a platform for policy makers to learn useful information from practitioners and service users, and thus improve dementia care policies and administration in Shanghai and beyond.

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## Notes

<sup>1</sup> China’s hukou is a family registration program that serves as a domestic passport, regulating population distribution and rural-to-urban migration.

<sup>2</sup> I call this type of eldercare institution as “mini-nursing homes” because of its smaller size than general nursing homes. More details see the following section.

<sup>3</sup> Comprehensive statistics about the current dementia sufferers in Shanghai or in the Bund may not exist, owing to rapid modernization, migration, and the separation of the site of one’s hukou registration and one’s residence. Dr. Zhang Mingyuan is a prominent psychiatrist. His epidemiological research on the prevalence of dementia in 1990 in another neighborhood of Shanghai is still valuable due to the inclusion of almost all residents at that time.

<sup>4</sup> There is a standard established by the Shanghai Healthcare Bureau to evaluate long-term care needs. This standard references many developed countries with long-term insurance.

<sup>5</sup> “Too old” traditionally refers to a life stage when one regresses to a status of childhood immaturity.

<sup>6</sup> I have a separate chapter discussing dementia-related stigma in China that appears in my dissertation “Between Tradition and Modernity: Experiences of Family Caregiving for Elders with Dementia in Shanghai, China.”

<sup>7</sup> This is based on my work experience and my archival research during the fieldwork.

<sup>8</sup> 1:4, 1:6, and 1:8 refer to one nursing aide to 4, 6, and 8 seniors correspondingly.

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