A LANDSCAPE OF DEMENTIA CARE

POLITICS, PRACTICES, AND MORALITY IN SHANGHAI, CHINA

By

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A Landscape of Dementia Care

Politics, Practices, and Morality in Shanghai, China

Abstract

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"A Landscape of Dementia Care: Politics, Practices, and Morality in Shanghai, China" addresses the impact of biopolitical discourses on the practice of dementia care and the associated moral struggles with family dementia caregiving during the process of modernization in China. The specific biopolitical discourses primarily impacting dementia care include the biomedical representation of dementia as a mental disorder rooted in biological malfunction of the brain and the national legislation underscoring the obligation of families to support and care for elders. As China has joined the global fight against dementia, a list of Western humanistic care practices have been introduced to improve the condition of dementia sufferers. Unfortunately, these Western practices have caused conflicts with traditional mode of dementia care. Contrary to the established view that care arises from caregivers' internal convictions, I argue that social configurations

have not only shaped new care paradigms, but also created tensions within care practices. These tensions stem from the conflict between biopolitical governance and local resistance, between technological care and hands-on care, and between traditional norms and modern ethics. From these tensions, new care paradigms are emerging. At the society level, these new paradigms include the neurologist-centered medical care (which is replacing the traditional psychiatrist-centered dementia care), the establishment of dementia-care units in eldercare facilities, and the advocacy of relational care for dementia sufferers. These different care paradigms complicate the biopolitical discourses, which further affect the perceptions and practices of dementia care among family caregivers. Within domestic settings, care as stewardship, in which family caregivers actively incorporates modern techniques to improve care outcomes, and resigned familism, in which family caregivers do not fully resign from caregiving nor are fully compassionate to patients, are two paradigms closely related to biopolitical discourses. Due to the overwhelming care burden, family caregivers face moral dilemmas of taking care of dementia sufferers. These dilemmas include fulfilling one's moral and legal duties without protecting individual rights and favoring collective interests by unwillingly sacrificing personal interests. Without effective social support, family caregivers have to figure out individual strategies to solve these dilemmas. Potential strategies include embracing self-care and revitalizing traditional beliefs (e.g., Confucianism, Buddhism, and Christianity) to bring moral comfort. By examining the politics, practices, and morality of dementia care, this project has unraveled changes of the power structure, dynamics of family-based care, moral dilemmas of family caregivers, and transformations in the meanings associated with dementia and care.

Introduction

On September 10, 2009, my mother called me from our hometown in Northern China to say that my grandpa had become "crazy." He did not want to stay in the nursing home, at which my two uncles spent almost 2000 RMB [$280 USD] per month for taking care of him. Instead, he ran away from the nursing home two weeks later. He insisted on staying with my two uncles to receive some family affection. However, both my uncles and their nuclear families were busy with their business. When my grandpa went home, he started to quarrel with everyone in the family. Sometimes he lost his temper and physically hit people. When my aunt was truly to give my grandpa some food, my grandpa bit her hand. Then, everyone became angry with my grandpa, and locked him in his bedroom. In order to get out of the room, he knocked down the door, broke the window, and even throw out everything in his room. These scenes were constantly haunting me when I was studying neuroscience in Fudan University in Shanghai. I was not around him when he died only three months later on a cold November night. Nobody was there: my two uncles were busy with their business, my mother and my aunt were with their families, and no one knew about his death until he was found the next morning.

This tragic story constantly made me feel guilty, because my grandpa had done so much for us, and we, as family members, had done nothing except ignore and even mistreat him. This tragic story forced me to change my potential career from being a doctor or a medical researcher to working to become someone who can prevent this kind of tragedy in China. When I started working in a local non-governmental organization (NGO) in

2010 in Shanghai, I found such tragedies were not limited to my family, and numerous Chinese families had elders suffering from dementia. Surprisingly, nobody wanted to talk about it, because “this issue does not deserve our attention,” “it’s a shame to the family,” or “what’s the point to talk about it if we can do nothing to change the situation?” Before 2010, these passive responses dominated the public attitude toward dementia and created problems. First, dementia was medicalized as a mental disorder, in which patients received care from psychiatrists, making it a stigmatized condition in China. Second, because of the stigma, most people living with dementia were undiagnosed and untreated. Third, dementia sufferers were excluded from eldercare institutions because of their “problematic psychiatric behaviors.” Compounding these difficulties is that the state enacted the traditional Confucian virtue of family eldercare as a legal responsibility in the Elder Protection Law in 1996. The result was that most dementia sufferers have to stay home and receive support primarily from their families, indicating that taking care of dementia sufferers is a private issue—rather than a public one—within these biopolitical discourses.

More recently, starting in 2010, the increasing number of dementia sufferers has transformed this issue from a private one to a public concern. In 2020, there were estimated about 14.1 million elders living with dementia in China (Xu et al. 2017). As China has joined the global fight against dementia, nationwide dementia-friendly initiatives have promoted a series of campaigns to change the biopolitical discourses. In Shanghai, non-state actors (e.g., psychiatrists, non-psychiatric medical professionals, NGO directors, nursing-home managers, media producers, and family caregivers) advocate to destigmatize this condition by reconceptualizing dementia as a neurodegenerative disease. These non-state actors also introduce Western humanistic care for dementia sufferers in eldercare institutions. In response, in 2017, the Shanghai government initiated the project of building dementia-friendly communities by 2030. At that time, most nursing homes in Shanghai started to enroll elders with dementia, and the government also began to subsidize these institutions to get them to build dementia-care units. More importantly, the Shanghai Civil Affairs decreed that discriminative words to describe dementia were not allowed in eldercare institutions.

This project examines the landscape of dementia care in Shanghai, China. Specifically, it addresses politics, practices, and morality surrounding dementia care during the process of modernization in China. Dementia care constitutes both traditional family-based eldercare and modern institutional care. Using ethnographic data gathered from interviews, participant observations, and archival research, I analyze how certain care paradigms are created, what kinds of tensions arise, and how family caregivers orient personal morality when certain forms of care fail to achieve ideal results.

Dementia care as a public issue offers us an opportunity to examine the relationship between Chinese state and society during the process of modernization. It is about how state and professional actors have been reconceptualizing this condition; how state and non-state actors have been negotiating a sociopolitical space for elders with dementia; and how each stakeholder is debating “good” care for this group of people. Furthermore, dementia care is an avenue to examine the dynamics of family culture on eldercare. Thus, this project examines how family politics of intergenerational relationship and gender ideology affect dementia care arrangements. It is also about how day-to-day care is actually performed in domestic settings, and how family caregivers engage with different forms of medicine and modern technology to navigate care. In a rapidly changing society, dementia care poses challenges to the family, so it is also about burden, and how family caregivers respond to the needs of dementia sufferers when there are competing values. A significant indicator for a modern society is the presence of professional services for dementia sufferers. As China is heading toward modernity, family caregivers have the opportunity to seek social support from the eldercare industry and biomedical institutions. So this study is also about the transitions of care and the associated meanings of these transitions. Lastly, this project is about moral encounters of family caregivers who have experienced rapid social changes in China.

As China has gradually joined the global fight against dementia, a list of Western practices have been introduced to improve conditions of dementia sufferers. Different modes of care between Eastern and Western societies have reconfigured new forms of dementia care. Contrary to the established view that care arises from caregivers' internal convictions, I argue that social configurations have not only shaped new care paradigms, but also created tensions within care practices. These tensions stem from the conflicts between governmental biopolitics and non-state actors' resistance, between technological care and hands-on care, and between traditional norms and modern ethics. From these tensions, new care paradigms are emerging. In the medical field, the general medical care that intends to destigmatize dementia is replacing the traditional psychiatric model. At the institutional level, dementia-care units are emerging as an effective strategy to supplement traditional family-based eldercare. From conceptual perspective, the state's promotion of systematic care and non-state actors' advocacy of relational care offer two frameworks regarding the organization of dementia care, which indirectly affect family caregivers with respect to dementia perceptions and care practices. Within domestic settings, case as stewardship, in which family caregivers actively incorporate modern techniques, and resigned familism, in which family caregivers feel ambivalent about modern practices, are two care paradigms in response to these biopolitical discourses. These different forms of care demonstrate various understandings of dementia, and how care is delivered, practiced, and constrained. By examining the experiential aspects of family dementia caregiving, this project has unraveled changes in family structure, transformations of family-based care, moral dilemmas of family caregivers, and the meanings associated with dementia and care.

Biopolitics of Aging and Care in China

Population aging is a major challenge for the future development of China. First, the aging population continues to grow. By 2019, China's population reached 1.4 billion, accounting for about 18% of the world's total (NBS 2019). The fertility rate declined from 7.5 in 1963 (Poston and Duan 2000), to 2.24 in 1980, to 1.5 in 2010, and to 1.7 in 2017 after the introduction of Two-Child policy in 2015 (The World Bank 2019a). At the same time, the decline in the mortality rate has caused an increase in life expectancy from 41 years in 1950 to 73.6 and 79.4 years for males and females respectively in 2015 (NBS 2019). According to the latest census in 2019, there were 167 million people aged 65 and above, accounting for 16.8% of China's total population (NSB 2019).

Second, ongoing population aging will threaten economic development. In China, population aging is characterized by "growing old before getting rich," which creates unprecedented challenges for the whole society (Shea et al. 2020). Despite the fact that China's GDP per capita reached $9,770.80 in 2018, the GDP in industrial societies remains much higher. For example, the GDP per capita in South Korea was $31,362.80, in Japan was $39,290.00, and in the United States was $62,794.60 (The World Bank 2019b). Although China has had the fastest growing economy in the world, this achievement is partly due to the demographic dividend with lower labor costs. China's working-age population started shrinking in 2014 (Cai 2016). Thus, it is estimated that the population aging will threaten China's current economic growth model by reducing the economic productivity of the work force. An economic transformation accounting for population aging is needed for ongoing economic growth.

Third, as a developing country with a huge aging population, China lacks a strong social system to deal with eldercare. Social support for seniors such as the pension system in urban China is characterized as a "pay-as-you-go" system, which is unsustainable in the long run (Chen and Turner 2014). The central government introduced a nationwide experimental rural social pension scheme in 2009 – the New Rural Pension scheme, which provides a basic pension benefit averaging 100 RMB ($14.0 USD) per month (Chen et al. 2018). While acknowledging that it improves the daily life of seniors in rural China, it is far from enough to provide solid support in terms of care. Replacing it with a fully funded system or combining with other social modifications, such as increasing the retirement age from 60 to 65, etc., is both necessary and challenging (Zhao and Xu 2002).

Finally, the ongoing population aging in China has out of necessity fostered a social environment of market-based eldercare (Zhu et al. 2017). Various forms of institutional care are emerging, including nursing homes, community-based eldercare, and senior centers (see Chapter 3). These forms of institutional care are public, private, or hybrid. Accordingly, charges and quality of care varies. In order to enable seniors' access to institutional care, in 2017, the central government initiated the long-term care insurance trial in several cities. The rationale was to financially support seniors who were in need of an intensive level of care (see Chapter 3). While acknowledging that these trials set a milestone for the further development of social eldercare, this form of support is inadequate to deal with numerous urban seniors who are physically and/or cognitively impaired. According to a news report, there were about 50 million elders physically or cognitively impaired in China in 2017 (Zhang 2018b), thus, about 100 million families were affected. Therefore, how to support these families and seniors is an urgent social issue.

The first aim of this project is to address politics of aging and care in China. So far, no published book-length ethnographic work conducted by anthropologists in China that I have been able to locate has focused on the experiences of age-related dementia care. This is quite remarkable since population aging and all that is associated with it is a “hot” topic, particularly since this country is undergoing dramatic social changes. As a result of these changes, there are many pressing questions that need to be addressed. Namely, what will happen in 2030 when there will be 23.3 million dementia patients (Xu et al. 2017)? How does the Chinese state respond to the increasing number of elders with dementia? How can families and social institutions care for these elders when 19.25% of its total population will be 65 and above in 2030 (Wei et al. 2019)? These are some of the very real and serious challenges that Chinese society will have to confront in the not-too-distant future. As such, responses of the Shanghai government, actions of non-state actors, and narratives of family dementia caregivers offer some insights into what is to come and how to plan for it.

It is imperative that we start to engage with and answer these questions. As a developing country with the largest number of dementia sufferers, China lags behind developed countries in terms of clinical research, community-based prevention, and implementing culturally appropriate care arrangements. Yet, that does not mean that China has made no preparations for the increasing number of dementia sufferers.

Like many other countries, one primary strategy that Chinese government has adopted to deal with the increasing number of dementia sufferers is biopolitics. According to Foucault, "biopolitics deal with the population, with the population as a political problem, as a problem that is at once scientific and political, as a biological problem and as power's problem" (1976:245). It is to ensure, sustain, and multiple life, to put this life in order. Thus, biopolitics is the intersection and mutual incorporation of life and politics. If we begin from this basic definition, a series of questions immediately arise: What is life? What is politics? What is the relationship between life and politics? Are all forms of politics productive or repressive to life? How do people experience politics relate to life? Different answers exist to these questions. For Foucault, life cannot be understood in terms of biological forces or determinants that exist outside of politics. Instead, life should be understood as both an object of politics and an effect of technological strategies. In other words, biopolitics exists in the form of disciplinary technologies and social institutions, which control and manage individual bodies and populations. Biopolitics intervene on aging bodies and populations through medical institutions, eldercare institutions, biotechnologies, and gerontechnologies. These strategies, in contrast to sovereign power, aim to develop, optimize, order, and secure life.

Medicalization is a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders (Conrad 2007). It can be glossed as a biopolitical strategy to deal with population aging through the rational application of science to everyday life. In non-Western societies, medicalization is closely related to the process of modernization and sometimes, colonization (Chiang 2014; Cohen 1998; Lock 1993, 2004). Thus, it inevitably serves as a strategy for the state to systematically monitor the health of individuals and populations.

Anthropological studies have documented the medicalization of bodily changes associated with aging, such as menopause (Lock 1993), sexual dysfunction (Wentzell 2013), and memory loss (Bond 1992; Gaines and Whitehouse 2006). Biotechnologies, such as drugs and medical procedures, have been used for treating and differentiating between the aging bodies that are "normal" and "abnormal" based on standardized medical evidence (Kaufman et al. 2013). Recently, the development of genetics, which aims to unravel mysteries of human physical, physiological, and behavioral variations, has become a new form of social control that monitors individuals' DNA codes for risks of Alzheimer's disease (AD) (Lock 2013; Lock et al. 2006). While acknowledging that medicalization of aging aims to legitimate medical care for patients, it also results in roaring healthcare costs (Conrad et al. 2010), a shifting culture of interpreting aging bodies (Estes and Binney 1989), and public anxieties about bodily changes (Beard and Neary 2013; Fishman et al. 2015; Schweda and Pfaller 2014).

Dementia is a multidimensional issue, which involves biological, sociocultural, political, and economic factors. Often these factors interact with each other in complex ways and, in turn, impact biological processes to shape the condition of the body over time.

Medicalization, as a biopolitical strategy, tends to reduce the experience of dementia to a biological experience. For example, there is a potential breakthrough for the treatment of Alzheimer's disease. So far, on the drug market, Donepezil, Memantine, Rivastigmine and other drugs help regulate the functions of cholinergic nerves or serve as neurotransmitter inhibitors, but these drugs do not reverse the progress of Alzheimer's disease (AD). In Sep 2019, Geng and colleagues (Wang et al. 2019) published an inspiring article that challenged the Western-dominated research on drugs for AD. This article introduced a marine source of oligosaccharide drug to regulate the microbiota and control the gut dysbiosis-promoted neuroinflammation in AD progression. In other words, this drug, to some extent, can reverse the progression of AD. In Nov 2019, this drug, Sodium Oligomannate Capsules (brand name Jiuqiyi 九期一), was approved by the Chinese Food and Drug Administration to improve mild and moderate AD patients. This breakthrough, even though controversial, might become a biomedical strategy to deal with the increasing number of dementia sufferers in China and beyond. Given the dominant biomedical discourse, problems associated with dementia need to be addressed through medications. In the haste to find cures through biomedicine, we tend not to recognize the sociopolitical problems.

Critiques about medicalization of dementia have mainly focused on associated ethical implications and the wider social impacts. The increasing number of individuals affected by dementia intensifies clinical ethical issues, such as genetic testing (Hedera 2001; Lock et al. 2006), diagnostic disclosure (Graham 2006; Lee 2019), agency and subjectivity of dementia sufferers in making decisions (Herskovits 1995; Smith 2006), and appropriate therapeutic goals and end-of-life care (Fetherston et al. 2018; Whitehouse 2000). Ivan

Illich (1975) argues that the world is suffering from too much medical interference, which has threatened the real life of human beings in the name of medical care. Medical anthropologists have argued that the biomedical model of care is inadequate to solve cultural norms and values regarding care relations and personhood of dementia sufferers, therapeutic narratives, and the structure of care (Aulino 2019; Kleinman 1988, 2019; Kleinman and Wilkinson 2016).

A significant social impact of medicalization of dementia is stigmatization of this human condition. Despite its clear benefits of medicalization, diagnostic labels serve as cues that activate stigma and stereotypes. Goffman defines stigma as “an attitude that is deeply discrediting within a social interaction” (1963:3). Individuals possessing such an attribute are different from others in ways that are undesired and shameful. The stigmatized individual is “reduced… from a whole and usual person to a tainted, discounted one” (Goffman 1963:3). Stigma associated with the diagnostic labels of dementia and its related condition such as mild cognitive impairment (MCI) can have a significant and negative impact on interpersonal relationships, interactions with the health care community, attitudes about service utilization, and participation in clinical research (Garand et al. 2009).

Comparing to the medicalization forces in the context of dementia, the social forces such as the stigma associated with diagnosing with dementia play a significant role in depriving the selfhood of the elders with dementia. For example, caregivers are often advised that when the person diagnosed with AD, it is the disease, rather than the person, that should be responsible for the inappropriate behaviors (Cohen 1998). However, this diagnostic label facilitates social and medical control of the individual and contributes to the erasure of the individual's subjectivity and agency. For example, Ballenger (2006) analyzes the formulation of stigma in the case of diagnosing AD and emphasizes that stigma is more than being attributed to something "wrong with them" or "brought the suffering on themselves" (Goffman 1963). Rather, stigma is the amount of anxiety surrounding the boundary between the normal and the pathological. Because AD is frequently described as a process characterized by loss or degradation of the being, individuals with AD are interpreted as unable to carry off their social roles as respectable individuals. They are deeply stigmatized for having this disease because of the "loss of self" (Herskovits 1995) and the "social death" (Sweeting and Gilhooly 1997). Thus, the diagnosis of AD is a much-feared stigmatizing label (Bond 1992) that carries with it the force of a sentence of social death (Robertson 1991).

While medicalization of dementia has been globally accepted, local responses to the diagnosis criteria, subtypes, treatments, and the associated stigma vary from society to society. Alzheimer's disease was first identified as a "brain disease" by Alois Alzheimer about a century ago, however, this disease lost its way in the medical field due to limited diagnostic equipment. Innovations of biotechnology such as the development of electron microscope have re-medicalized dementia since 1960 (Lock 2013). In the US, while organizational changes (e.g., the establishment of National Institute of Aging) and increasing activities call for research, social services, and public awareness, these activities ultimately politicize dementia and legitimate dementia care and the cure of dementia. Despite the good intention of medicalization, stigma associated with dementia remains a serious social issue in the US (Ballenger 2006). In Asian societies such as Japan, South Korea, India, and China, medicalization of dementia is closely related to modernization and the ensuing population aging and the increasing number of dementia sufferers (Cohen 1998, Traphgan 2000; Lee 2019; Zhang 2018c). Due to different cultural understandings of dementia, this illness condition carries severe stigma in Asian countries, in which stigmatized terms are used to describe dementia conditions. For instance, in Japan, *chihô* is the official diagnosis of dementia, which carries strong stigma. In response, in 2004, medical professionals in Japan suggested the government should replace the *chihô-shô* with the term *ninchi-shô* to reduce the stigma associated with the diagnosis (Ikeda and Roemer 2009). Although the indexical name of dementia was changed, but the original diagnostic classification did not change. Thus, social stigma for this label still exist.

This project examines biopolitical discourses of dementia and contextualizes local responses to the medicalization yet stigmatization of dementia in Shanghai. What are the written policies of the national and local governments, which address issues surrounding dementia and dementia care? What are the effects of the legislation on family dementia caregiving? How is dementia conceptualized in China now by different social units (e.g., the government, medical institutions, eldercare facilities, and popular media) and by different social actors (e.g., the state, medical professionals, service providers, family caregivers, and the public)? How and why has such an illness become stigmatized? How do state and non-state actors respond to the stigma of dementia? Are there any local activities to de-stigmatize dementia and advocate on behalf of seniors with dementia and their caregivers? If so, in what ways?

Theory of Practice and Dementia Care

Bourdieu’s practice theory (1990) offers an alternative way of understanding and explaining the experiential aspects of life. The philosophical premise of practice theory is that the social world—such as individual and group activities—is brought into being through practice (Rouse 2007). Bourdieu recognizes that the actions of social groups cannot be explained simply as the aggregate of individual behaviors, but rather as actions that incorporate influences from cultures, traditions, and social structures (Jenkins 1992; Rhynas 2004). These influences are incorporated into his theory through the concepts of field, capital, and habitus to elaborate the inherent relationship between structure and action.

In Bourdieu’s theory, the field can be framed as a series of structures, institutions, authorities, and activities, all of which are related to individual actions. Field is not a static entity; rather, it is always changing as practices or power dynamics challenge its boundaries. Capital represents the power of a person and can be exchanged or used in order to improve his/her position within the field. It can take various forms, including symbolic capital, cultural capital, and economic capital. The exchanges among various forms of capital and their close connection with power are key to the reconfiguration of the field. Habitus represents the interaction between individual actors and cultural and traditional aspects of life. Cultural, religious, and historical practices are explicit examples of habitus, whereas socialization such as modesty is an implicit example. Habitus is an embodied reality that is often unquestioned because of its inherent nature. These concepts lay a foundation to articulate the relationship between the practice theory and dementia care.

The focus of practice theory is on dynamics and relationships, which make it an appropriate lens for examining dementia care. The field, as described by Bourdieu (1990), should be conceived as dynamics of relationships rather than individual actors. The social environment, the organizational structures of the hospital, and the wider structures of society will influence how dementia care is conceptualized and unfolded. Public education, science, medicine, and media all play a significant role in this process and are influential in shaping the field of dementia care. Within this field, dementia sufferers, family caregivers, nursing home directors, medical professionals, and many other stakeholders interact with structural factors to negotiate the direction and practice of dementia care. Thus, relationships and interactions between individual actors and the structures of the field have the potential to alter the stability and produce changes in that field. For example, the nationwide dementia-friendly campaigns in China should be understood as an attempt to transform the previous psychiatric model of dementia care, in which the homogeneous central state provides service to a passive public via psychiatrists, toward one where the state and psychiatrists are but one part of the social care model. The field changes over time as environments of care, legislative programs (e.g., dementia-care units), and authority of medical institutions are always being established and re-established through social activities.

Capital is another dimension to understanding dementia care. Bourdieu did not intend capital to be understood only in economic terms; however, he recognized the importance of economic capital and the resultant social stratification in modern society. Practices of care are first of all influenced by modern technology. Individuals who are in better economic circumstances have access to biomedicine and gerontechnology to improve care outcome, whereas those in poor conditions might be shied away from these modern practices (Chen and Wellman 2015; Endter 2016; Silver 2014). Symbolic and cultural capital[1] are also important to understanding dementia care. In an eldercare setting, it is evident that there are differences between the assignment of capital to those cognitively intact and those with dementia. Dementia sufferers often have less opportunity to contribute to decisions about their care, reducing their power to influence their own health condition (Kontos et al. 2016). Dementia-care units serve as an instance of the symbolic capital that reconfigures the field. While acknowledging that people living with dementia might have less capital within care settings than people who are cognitively intact, research has suggested that there are some benefits associated with the label of dementia in the culture of eldercare facilities. People living with dementia are seen as legitimizing withdrawal from social responsibilities without incurring any sanction from the community (Smith 2006). Therefore, some cultural capital can be identified and protected with the label of dementia.

Building upon the work of these scholars, my research supports the notion of economic capital and the bifurcation of symbolic and cultural capital as important factors associated with practices and forms of dementia care. Yet, I also found that there is a synergic effect between economic capital and symbolic and cultural capital in the case of family dementia caregiving. Family caregivers with better economic conditions might not turn to modern medicine and gerontechnology. This is because using these services can activate the stigma—the symbolic capital—that can adversely affect the quality of life of

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[1] Symbolic capital and cultural capital are two different forms according to Bourdieu. I consider these two forms of capital to be exchangeable in understanding the associated stigma of dementia.

dementia sufferers. By contrast, in families where there are limited resources, family caregivers use their agency to fashion low-end but effective care devices to improve care outcomes. For example, a more well-off family can afford an out-of-pocket drug to potentially improve the dementia symptoms of their kin, while a less well-off family might practice day-to-day memory training. Similarly, some families can afford an expensive ventilator to improve the overall health condition of dementia sufferers, whereas other family caregiver turn to be technicians to create their own care devices such as an alarm to monitor urine and feces and keep patients clean (Chapter 5). Under these conditions, stigma has little impact on the practice of dementia care, which implies that symbolic and cultural capital protects dementia sufferers from the labelling effects associated with dementia. These examples from dementia care highlight the insights that could be gained from exploring the concept of capital more fully in order to explain and potential improve practice in the field.

Bourdieu's habitus can also be employed to analyze the practice of dementia care. The stigmatization of people living with dementia is an example of habitus, which is influenced by history, tradition, customs, and principles in various societies. Building upon the concept of habitus, dementia-friendly campaigns in China can be understood as a reestablishment of the habitus of dementia care (Chapter 2 and 3). By demonstrating positive attitudes to and specific ways of interacting with dementia sufferers, advocates are transforming the landscape of care. For example, in dementia care facilities, nursing aides might observe colleagues' attitudes to dementia sufferers. Demonstrations of respect for dementia sufferers, the value attached to confused discourse, and strategies to alleviate distress may all form part of the habitus of dementia care. As I found during my fieldwork, factors contribute to a new habitus of dementia care include biomedicine, alternative care, and gerontechnology (Chapter 5). I call this emerging *care as stewardship*, in which family caregivers engage in modern medicine and technology to improve care outcomes. Likewise, people use their personal history and experience to shape public responses and attitudes toward dementia sufferers. The experience of family caregivers might be directly influential. I found most advocates for dementia sufferers in Shanghai have personal experiences of family caregiving. The transformation of advocates' personal experience to a political issue offers a possibility for producing change with every action and reproducing stability of dementia care.

While acknowledging that these contributing factors are effective to initiate new paradigms of dementia care, traditional practices are not uncommon in Chinese society. Folk understandings of dementia, the entrenched stigma, and inadequate social support for dementia sufferers and their family caregivers co-construct a practice of *resigned familism*, in which family caregivers do not fully resign from caregiving nor are they fully compassionate to their kin (Chapter 6). Family caregivers reject modern medicine and technology in care practice. This rejection questions biological causality of dementia and the effectiveness of modern technology on the one hand, and the intimate relationship between dementia sufferers and family caregivers on the other. Resigned familism creates ways of organizing care, and care practices constitute resigned familism. This continuous coproduction of practice and social environment means neither is static; rather, they are constantly being adapted and refreshed (Bender and Feldman 2015).

Building upon practice theory, I argue that dementia care can be understood as embedded in the activities and practices occurring in the field, rather than a manifest structure independent of the activities occurring within them. Practices of dementia care can transform social structures (e.g., medical institutions, social environment, modern technology, and eldercare facilities) in ways to make them more or less conducive to caring for dementia sufferers just as structural constrains and enables practices of care.

The Limits of Morality and Negotiated Meanings of Dementia Care

How are we to understand and live our lives when the moral and legal demands require more than we can give? I raise this question in the global context of an aging population and the ensuing trend to return to families the long-term care of the chronically ill. The assumption behind the promotion of this trend is that, with some modest support from the government, families have the moral, psychological, and spiritual capacity to provide and manage long-term care. Following the same logic, the Chinese government mandates that families should take primary responsibility for eldercare, while social services for elders are underdeveloped. A supporting motive is the widespread belief that filial piety is a traditional Confucian virtue, notably kinship practice and family integrity. Thus, endorsing this traditional value not only lays a moral foundation for Chinese society, but also fulfills one's moral and legal obligation. When an increasing number of seniors need a lot of care, the provision of such care by families turns to be inadequate and insupportable.

Eldercare as a kinship practice has its limitations because the performance of this practice is associated with the moral foundation of a society. Anthropological studies show that rapid population aging and modernization affect local values and norms related to performing family caregiving for elders (Brijnath 2014; Ikels 2004; Shea et al. 2020). Specifically, changing gender roles (Mendez-Luck et al. 2008; Shi 2017c), changing demographic structures (Cohen 1998; Powell 2012; Traphagan and Knight 2003), and eroding family values such as filial piety in China (Ikels 1993, 2006; Yan 2016; Zhang 2009) and familism in Mexico (Gomes and Montes 2008), India (Brijnath 2014; Cohen 1998), and countries of Sub-Saharan Africa (Ugwu 2010), all contribute to the modern "caregiving crisis" (Jesmin et al. 2011). Scholars further demonstrate that the growing divergences in filial norms have intensified intergenerational conflicts and increased elder mistreatment in family settings (Dong et al. 2008; Ferreira and Lindgren 2008; Shankardass 2008; Zhang 2016). In developing countries such as China, rapid modernization has created a "moral crisis" where collectivism and individualism interact with each other in shaping people's daily lives (Kleinman et al. 2011; Yan 2009, 2010). All of these phenomena point to the limits of morality to carry out eldercare as kinship practice.

While acknowledging that there are limits of morality to sustain eldercare as kinship practice, people are in principle willing to care for a family member. The universal practice of family-based care still serves as a backbone for each society to ensure its continuing survival and wellbeing. Where can people personally find the necessary moral resources to sustain their commitment and to make meaning of their day-to-day care? What is the basis of moral obligation in the case of family dementia caregiving? If Chinese people have an obligation to care for family members when the need arises, what are the limits of that obligation? How can family caregivers in China make their duties emotionally satisfying or negotiate the meaning of their self-sacrifice?

Anthropological studies have made significant contributions by examining the meaning of dementia and dementia care. Pia Kontos (2005), Annette Leibing (2006), John

Traphagan (2000), Lawrence Cohen (1998), and Charlotte Ikels (1998) have illustrated the cultural construction of self and personhood of dementia sufferers in different societies. Although with different understandings, the centrality of dementia care is moral obligation (Brijnath 2014; Lee 2019). Based on their personal experiences with family members suffering from dementia, Arthur Kleinman (2009, 2012, 2013, 2019), Janelle Taylor (2008), and Sharon Kaufman (2017) have shown that care is a moral practice embedded in relations of memory, power, and identity. Kleinman (2009:293) argues that caregiving is a moral practice "that makes caregivers, and at times even the care receivers, more present and thereby fully human." Mol (2008:1) further makes care explicit by stating that caregiving "make[s] daily life more bearable." Moral engagement, a process of transforming the illness from a disorder to a meaningful way of life (Brijnath 2014), sustains heroic and extraordinary caregiving. This kind of caregiving often pushes family caregivers to go beyond the ordinary boundaries of morality.

While acknowledging that moral engagement lays a foundation for family caregiving, morality in general, and self-sacrifice in particular, cannot be sustained by will alone. In the real world, family caregivers have limited capacities to take on the heavy moral burden of dementia care, particularly when dealing with excessive care demands. For example, there is a considerable agreement that adult children should take care of parents if demands are not great. However, when self-sacrifice encounters heavy, increasing care burden, the limits of moral obligation will be pushed or challenged. Potential results of pushing family-based care can be elder neglect, work-care conflicts, an increase in divorce, and the deterioration of caregivers' health conditions (Dong et al. 2008; Robison et al. 2009; Schulz and Martire 2004).

In this project, I aim to examine moral dilemmas of family dementia caregivers and how they solve these dilemmas. I call these caregivers "the generation in the middle," and contextualize their moral struggles in terms of a longer history. These caregivers were born in or before 1960s, trained by traditional Confucian values in early stages of life, experienced radical Maoist ideology during the Cultural Revolution, and later encountered modernization in the reform era. Rapid social changes make them more susceptible to moral controversies, such as their perceptions of dementia and practices of care. Family caregivers' moral controversies are directly related to their subjectivities, which are formed, cultivated, and negotiated at the intersections of capitalist economy, state power, and individual responsibility. Interestingly, in order to solve these controversies, family caregivers turn to revitalize old forms (e.g., religious practices) and engage in new forms (e.g., self-care) of morality.

Dementia never exclusively impacts the lives of those sufferers. It is thus a critical site to examine the diverse ways that the Chinese people react to this public epidemic. In this study, I am explicitly concerned with dementia-friendly campaigns initiated by non-state actors to destigmatize this illness, a synergetic effort to transform the moral landscape of dementia care. I argue that nationwide dementia-friendly campaigns have challenged the power structure that constructs the moral world of dementia sufferers. Specifically, Chinese neurologists and gerontologists intend to reconceptualize dementia as a neurodegenerative disease rather than a stigmatized mental disorder classified by the state. Moreover, the local NGO's introduction of Western humanitarian approach enriches the moral landscape of dementia care by integrating the person-centered care (Kitwood 1990) with local care ethics. Even though stigma has indeed diminished after these campaigns, its persistence continues to be all too often apparent. These contending values in Shanghai reflect distinct moral frameworks of care for elders with dementia.

Shanghai as a Fieldsite

There are both personal and rational reasons to choose Shanghai as my fieldsite. My work experience in a local NGO from 2010 to 2013 allowed me to receive the support from local cadres necessary to conduct data collection in China (see below). In addition, my college education as a clinical gerontologist and my master education in neuroscience in Shanghai also provided me with the necessary knowledge about dementia care and its challenges for families.

The rapidly growing older population in Shanghai offers an opportunity to examine strategies that Chinese society has adopted to deal with the challenges associated with eldercare. Shanghai has experienced a record-setting increase in its aging population. According to the Shanghai Research Center on Aging, the total population was 14.6 million in 2018, of which 34.4% were elders aged 60 and above (about 5.03 million, SRCA 2019). With a growing elderly population, the number of dementia sufferers will also continue to rise. It was estimated that more than 14.1 million elders suffered from dementia nationwide in 2020 (Xu et al. 2017). In Shanghai, there were at least 168,450 elders with dementia in 2018.[2] Dementia deserves special attention because it requires intensive caregiving, which provides an opportunity to scrutinize the eldercare system, the social security system, and family-based care in Shanghai.

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[2] In 2018, there were 3.37 million elders aged 65 and above in Shanghai. Based on these statistics and the average incidence of dementia— 5% among elders aged 65 and above (Zhang et al. 1990)—there were more than 168,450 people with dementia in Shanghai.

For a long period of time, Shanghai has served as the experimental site for many social policies in China, including the development of the eldercare system (Zhu et al. 2017). Shanghai deserves our attention because it has developed a preliminary eldercare system, including in-home care, community-based care, and nursing home care. More significantly, Shanghai began a trial of long-term care insurance in three districts when I did my fieldwork in 2017 and expanded this social policy to all communities in 2018. Although this eldercare system is not robust in many ways, it provides both financial and social support to many families with elders, and offers alternative choices for family caregivers. Given the ongoing debates surrounding these policies, I introduce the eldercare system in Chapter 3. In the following part of this section, I introduce the social security system and the housing reform in Shanghai.

The Social Security System

Shanghai is well-known to be the most developed city in China. The per capita GDP contribution of Shanghai amounted to around 135,000 RMB, which exceeded 20,000 USD in 2018. With the largest GDP contribution in China, Shanghai has developed a comprehensive social welfare system, which mainly includes healthcare insurance, unemployment insurance, work-related injury insurance, maternity insurance, commercial/supplemental health insurance, and housing fund and pension programs. Because this project is about dementia care, I will focus on the reforms of pension and healthcare insurance in China, and Shanghai in particular.

The social security system in China was created by the labor insurance regulation of 1951, which consisted of pension insurance, medical insurance, mortality insurance, maternity and childcare insurance, natural disaster insurance, and family insurance (Sha

2007). Initially, the system was funded solely by state-owned companies,[3] and no contributions were made by staff and workers. Fund shortages were financed by a higher level of the labor union. Basically, the company took charge of every aspect of the welfare of its employees. Since its introduction, social security coverage had not been universal. In the Mao era, only qualified company staff and workers in urban areas were covered, whereas the agricultural population, which comprised over 70% of the total population, was excluded. As the largest city in mainland China, most citizens in Shanghai worked in industrial production, and thus were covered by the social security system (Sha 2007).

The sustainability of the social security system was challenged due to the Cultural Revolution, the increasing number of retirees, and the decaying state-owned enterprises in the 1970s and 1980s. Due to the lack of funding, the pension benefits and medical insurance expenses of many retirees completely relied upon their employers. For example, in Shanghai, pension benefits for retirees comprised 28.6% of total wages in 1984 (Sha 2007). In the late 1980s, some state-owned enterprises could not even pay out wages to staff, and thus stopped supporting pension payments and healthcare insurance.

Social security reform was initiated in 1992 to revert the company-administrated insurance system into a social security system to ensure its sustainability. The core part of the new system is called basic insurance: basic pension insurance, basic medical insurance, and minimum benefit levels guarantee minimum living standards for persons covered by social security. Under the new system, pension and medical insurance are

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[3] All companies were state-owned during the Mao era in China.

augmented with supplementary company insurance and individual insurance (Dorfman et al. 2013). The first characteristic of this new social security system is the introduction of premium payments by individuals. During the era of company-administrated insurance, funding was almost entirely the responsibility of companies. Since the 1992 reforms, funding responsibility of the new social security system has been allocated among individuals, companies, and the state. The second characteristic of the security reform is the introduction of individual accounts for pensions. In the individual pension account, the individual and employer each pay a monthly premium, which is accumulated in the account to earn interest. The individual receives a fixed monthly payment from the account after retirement. The third characteristic of the social security system is regional difference. While China’s social security law was promulgated by the central government, its administration and specific details are governed by local authorities. For instance, for each benefit, the employee and employer contribution rates and base differ as per the local jurisdiction and are subject to annual changes and reforms. Because this new security system is administrated by local governments, there are huge regional differences. For instance, the pension benefit in Shanghai in 2018 (4278 RMB [$599.0 USD] per month in average, SRCA 2019) was much higher than the monthly average pension in less developed urban areas in China (2870 RMB [$402.0 USD] per month in 2017; Fang and Feng 2020; Liu and Sun 2016). This is contributed by both the hukou system and the local GDP of each city/province. In the Mao era, the hukou system was to make distribution of state services through work units and communes easier and to better organize the population in preparation for a collective action. In the reform era, the hukou system serves as a tool to regulate rural-to-urban migration and access to social benefits. The regional disparity of pensions is directly affected by one's hukou registration place.

Reforms to China's healthcare insurance system follows the same logic as this reform of the pension insurance. Because of these systems' linkage to the hukou system, people without a Shanghai hukou cannot use the same healthcare insurance as those with a local hukou in Shanghai. When I did my fieldwork, healthcare insurance was reformed again to reduce this regional difference. That is, people who carry a non-Shanghai hukou can use their healthcare insurance in clinics in Shanghai, yet with a lower reimbursement ratio. In order to get more reimbursement, patients have to get a referral statement from doctors in their original living place. Therefore, hukou still serves as the primary hurdle for people to get access to the same benefit.

The Chinese government is working on providing affordable basic healthcare to all residents and enlarging pension coverage ratio to 95% of the total population by 2020. So far, about 95% of the total population has at least basic healthcare insurance coverage. The exact number of pension coverage nationwide is unknown so far.. In Shanghai, about 92.4% of the population aged 60 and above were covered by the pension scheme in 2018 (SRCA 2019). Senior citizens who had an urban hukou in Shanghai had an average pension of 4278 RMB [$599.0] in 2018.

While acknowledging that there is a breakthrough of the social security system in China, we should note the existence of the disadvantaged groups. For example, about 0.6% of senior citizens in Shanghai aged 60 and above primarily relied upon government subsidies in 2018 - the minimum living allowance, which was about 880 RMB [$123.2 USD] per month (SRCA 2019). People who enrolled into this program are often those without an official work history. Seniors with an advanced age such as those in their 90s or older often had an unofficial work record, which turned out to be a challenge for them to get pensions from the state. Those sent-down youth who returned to Shanghai after their retirement are another disadvantaged group who could not have equal benefits with their counterparts. Sent-down youth were a group of people who left their hometown and work in rural areas from 1950s to the end of the Cultural Revolution. Since 1976, some sent-down youth gradually returned to their original living place. Because of regional differences, the pensions and healthcare insurance of those sent-down youth follow the standards of their original working places, even though they are allowed to officially register as Shanghai citizens.

My research reveals a similarly inequitable trend in accessing the healthcare insurance and pension programs. Among the 144 families I interviewed, most family caregivers and care recipients had their pension and health insurance. Only two seniors who were dementia sufferers had no official job during the Mao era. Two family caregivers of the working age were unemployed when I conducted my fieldwork. One had been unemployed for more than ten years and primarily relied upon government subsidies. The other was unemployed temporarily for half a year in order to take care of her mother and later started an online business after I finished my fieldwork. For these family caregivers and care recipients, the minimal living allowance was their primary income. Healthcare insurance affects these disadvantaged groups similarly. The Shanghai government stated that basic healthcare expenses would be covered by the government if applicants reported their expenditures. According to these disadvantaged family caregivers, the process to apply for a medical care reimbursement turned to be very complex, and sometimes local cadres were reluctant to help applicants. The most disadvantaged group is the sent-down youth who returned to Shanghai after their retirement. Nine of the 144 family caregivers belong to this category. Only one of them had a monthly pension higher than the average pension in Shanghai due to his extraordinary work profile, and the remaining eight had a lower pension than the Shanghai average. Their healthcare insurance works in a similar vein, which often places an additional burden on these family caregivers.

Housing Reform and Family-Based Eldercare

Housing is an unavoidable topic when talking about eldercare in Shanghai. From 1949 to 1978, work units were in charge of housing for their workers in urban areas. Most Shanghai citizens lived in public houses, usually two or three generations living together within a very limited space. The situation became more serious when the sent-down youth returned to Shanghai after 1976. This was primarily due to limited housing resources. Residents usually include other family members' hukou in their public houses in order to show their hardships and to apply for another set of public house for amenities (Davis 1993). Although the living condition was harsh in the collective era, eldercare for the older generation could be ensured by family-based care.

From 1978 to 1988, a series of housing reform programs were tested in some parts of Shanghai following the national pragmatic approach. These programs were small scale and didn't significantly affect living patterns in Shanghai. In 1988, the first state official paper relating to urban housing reform in China was introduced. The primary aim of housing reform was to facilitate the withdrawal of work units from the responsibility of providing and maintaining housing for their workers and to foster a sense of self responsibility to invest in housing. To a large extent, this recent housing reform was a reversal of the housing policy in the Mao Era. Individuals and even some work units were quite skeptical of this state policy during the early stage of housing reform (Zhang 2010). In order to promote the privatization of housing ownership, the state had tried different approaches to accumulate capital for the further development of real estate. Strategies at early stages of housing reform included the sale of new housing to urban residents, subsidized sale of new housing, increasing rents for public houses, etc.

During these early stages, an individual—most of my informants who are currently elders—could get a private house, either through the commercial market or through the land acquisition act. However, due to limited financial ability and the massive laid-off actions of state-owned companies, most of my informants, particularly the adult children, could not afford to buy a house on the market. The majority who eventually occupied a modern house or apartment were through land acquisition. In other words, their money to buy a new apartment came from the compensation by the government and real estate industry during the land acquisition. Because of the financial inadequacy to afford new houses, adult children who are in their 50s or 60s turn to their parents' houses to get future amenities. The resulting housing privatization with a rapidly rising real estate price meant that those elders have controlled valuable assets worth fighting about.

The 2001 land acquisition policy was based on the number of registered hukou in the household and provided compensation that depended upon the commercial price for the living area as well as the negotiation with real estate developers. Since my field community was located in the inner city, the compensation for relocation was about 100,000-200,000 RMB [$14,000-28,000 USD] per registered hukou between 2008 and 2010. Considering the huge amount of compensation, a lot of households would take this policy loophole by registering as many hukou as possible for the future amenities. The later amended land acquisition policy in 2013 takes into account the size of the household and the commercial price of the demolishing area. However, since hukou still accounts to some extent for relocation compensation, residents keep on registering many hukou in their public houses, which makes the future demolishing and relocation too expensive to implement. At the same time, because of the potential amenities, those adult children who have registered their hukou in their parent's house will negotiate their care responsibility and housing inheritance rights with their siblings and parents (Zhang 2016).

Overall, a rapidly aging population and a relatively well-funded social security system have made Shanghai a fertile ground to examine the politics, practices, and morality of dementia care in China. Moreover, the state's emphasis on family responsibility for eldercare and the rising real estate price in Shanghai have further complicated the landscape of family dementia caregiving. At the time of my research, family caregivers are the primary care resources, even though there has been a dramatic change of social services for dementia sufferers.

Research Chronology and Methods

My exploration of dementia care started when I was a project manager for a local NGO between 2010 and 2013 in Shanghai. At that time, my colleagues and I tried to introduce the Western humanitarian care model for dementia sufferers into a community called the Bund. One purpose of this project was to provide social support for family dementia caregivers. I was able to participate in community activities and conduct interviews with various stakeholders, especially family caregivers about their daily struggles. After I started my doctoral program in the U.S. in 2013, I visited this community each year until 2017.

Data presented in this dissertation were mainly collected during ethnographic research on governance and dementia care between 2014 and 2017, a total of twenty months of fieldwork. The twenty months I spent in Shanghai included annual short visits, mostly in the summer, between 2014 and 2016, and the entire year of 2017. The primary settings of this project include a residential community—the Bund—and a memory clinic. The empirical data consists of in-depth interviews with 38 family caregivers in the Bund, and 106 family caregivers in the memory clinic. Family caregivers were included in the sample if they were Shanghai citizens aged 18 years or above and taking care of a dementia sufferer with/without an official diagnosis for at least a month. Respondents were recruited in a variety of ways. The 38 family caregivers in the Bund were recommended by community volunteers, and the 106 family caregivers were chosen randomly based on their regular visits to the memory clinic (as I will discuss below). I did not use official diagnosis of a specific type of dementia, given the privacy issue and the severe stigma associated with this condition in China. Regarding cases without an official diagnosis, however, family caregivers and other neighborhood residents all acknowledged that there were typical dementia symptoms of their kin, e.g., memory decline, wandering, repetitive questions, and body maintenance care work.

Ages of care recipients ranged from 52 to 101 years old, with the median age 79. Similarly, there was a broad age range of family caregivers, from 28 to 91 years old (median age 69). About three quarters of family caregivers aged 60 and above, and those below 60 years old were either retired,[4] (temporarily) unemployed, or in part-time jobs. Approximately 46.1% were male caregivers and 53.9% were female caregivers (more details see Chapter 4). All of these caregivers and care recipients had their household registration (hukou) in Shanghai.

Due to the comprehensive pension and healthcare insurance systems, there were no distinct differences in terms of economic circumstances between family caregivers from the Bund and those from the memory clinic. Most family caregivers were born in or before the 1960s. Because of the Cultural Revolution and other social movements during the Mao era, education levels of family caregivers were generally flat. Thus, education cannot be a reliable factor to distinguish one subject from the other. Since most family caregivers are seniors or retired, I turn to pension as a primary indicator of economic circumstances.

Given the comprehensive pension and health insurance systems, as well as the fact that all family caregivers and care recipients have a living place, the majority of families were middle class (n=131), the remaining relatively poor (n=13). The highest pension reported from one caregiver and one care recipient was about 15,000-20,000 RMB [$2,100-2,800 USD] due to the fact that they participated in the Civil War and contributed a lot to the liberation of the country. The majority of family caregivers and care recipients have their monthly pension ranging from 3000 to 7000 RMB [$420-980 USD] (see details in Chapter 4). The exact pension varies from case to case due to the years of work history, regional differences, and types of employment. Among the 144 family caregivers, only

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[4] The retirement age in China currently is 60 for men and 55 for female civil servants and 50 for female workers. By 2038 there will be an equal age for women and men set at 67.

thirteen reported that their monthly income was less than 3000 RMB [$420 USD] per month. Only one family caregiver of working age was unemployed and had completely relied upon government subsidies for more than ten years. The rest of those with a lower pension were former sent-down youth and those who had a short work history. Regarding the 144 care recipients, two care recipients had no pension, but relied on government subsidies (790 RMB [$110.6 USD] per month in 2017 and 880 RMB [$123.2 USD] per month in 2018) because of their advanced age and lack of formal work experience. Simply relying upon government subsidies is not enough. Many adult children in Shanghai provide various degrees of financial support for their parents, especially those in disadvantaged conditions. In some conditions such as those in need of surgery, adult children often pay the out-of-pocket portion for their parents. Thus, ascertaining a monthly income for this group of people was not possible, as their monthly incomes fluctuated considerably.

These pensions serve as the primary source for their daily needs, including life necessities, healthcare (out of pocket payment), and personal spending. According to all family caregivers, their care recipients had independent bank accounts, which meant they had no common finance. For instance, a husband caregiver and his wife who suffered from dementia had independent bank account for pensions; and a retired son and his mother suffering from dementia also had different bank accounts. Even for those care recipients who did not have a pension but relied on government subsidies, they equally had their bank accounts to record the monthly subsidies. These pensions or subsidies from the government, to a large extent, enabled both family caregivers and care recipients to be financially independent from their adult children. If they were hospitalized and in need of a surgery, patients had to rely upon their personal savings. Moreover, most households in China have personal savings, which, in most cases, would enable them access to healthcare.[5] More importantly, after four decades of reform, housing becomes the most valuable asset in Shanghai. Most family caregivers reported they had their own places to live, except for several former sent-down youth (see Chapter 4, 6, and 8).

The Bund, or Waitan Community, is located at the center of Shanghai (see Figure 1), at the intersection of Huangpu River and Suzhou River. It belongs to the Huangpu District, its upper level administration unit. It is well known as a tour site because of shopping centers such as Nanjing Road, the modern building complex, and numerous historical and cultural sites. The Bund is about 2.18 square kilometers, of which 1.85 square kilometers are dry land. According to the Sixth Population Census in China, there were 64, 896 people whose hukou was registered in Waitan. The exact number of people living in the Bund was unknown because of in- and out- migration, including the migrants from outside of Shanghai and people migrating out of the community to other communities or abroad. More than one third of the total population (39.3%) were seniors aged 60 and above in 2018 (SRCA 2019). Therefore, eldercare is a key topic in the domain of Civil Affairs.

The Waitan administrative community is comprised of 19 residents' committees. These committees are in charge of various neighborhood events, including allocating subsidies to those poor, elderly, disabled, and sick; mediating disputes; and organizing regular

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[5] Household Saving Rate in China decreased to 36.10 percent in 2016 from 37.10 percent in 2015. Personal Savings in China averaged 33.59 percent from 1992 until 2016, reaching an all-time high of 39 percent in 2010 and a record low of 27.20 percent in 2002. Data comes from: https://tradingeconomics.com/china/personal-savings.

events (e.g., health education, dance or singing performances, health examinations, home visits, etc.). During my fieldwork, most events were assigned to some community residents, or alternatively, nearby volunteers actively organized events in their neighborhoods. Basically, each month had at least two or three events. In some months such as January, February, September, and other months which had holidays, neighborhood events took place more frequently than in other months.

In addition to residents' committees, the Bund has developed a preliminary service system for seniors. This includes: two senior centers, with one removed in 2016 due to a subway project, and another one was modified into a dementia-care unit in 2017; a newly-established community-based mini nursing home, which drew severe resistance from local residents (see chapter 2); a public nursing home sponsored by local government, which was always full and its services were never satisfactory to the residents; and an information center, which provided consultation services and a public space for seniors to discuss news or social policies. During my fieldwork, I was able to talk to four government officials (two directors of the neighborhood residents' committee and two cadres in charge of eldercare) in the Bund about their plans for the further development of dementia care, and about a list of policies that were augmented by the Shanghai government. When available, I also served as a volunteer for various centers. This enabled me to talk to many residents, seniors, family caregivers, and staff in these centers, as well as to conduct participant observation in these settings. Sometimes, I was invited to give presentations about strategies to prevent dementia in these community centers.

My connections with family dementia caregivers in the Bund should be attributed to a group of people who called themselves “yongnianlou” volunteers. This group had 17 volunteers, with two males and 15 females. They were all retired, with an age range from 53 to 70 years old. Each volunteer came from a different residents’ committee and provided regular home visits to about 20-30 families with elders in need of intensive home care. Basically, 17 residents’ committees in the Bund were covered by services provided by these volunteers. The remaining two committees, for various reasons, rejected these services, and no volunteers joined this program. The “yongnianlou” volunteers were originally organized in 2011 when I was a project manager in the local NGO, Xintu (as will be discussed later). After the NGO left, this group of people continued to work in the community, providing services to families with dementia sufferers as well as to numerous other families in need of support. It was registered as a non-profit social organization in 2017 when I conducted my fieldwork. Like many other social organizations in China, its financial resources were multiple—government funding, social charities, entrepreneur donations, and other resources. Because all volunteers were from the community, for residents in the community, and administrated by the community, this group of volunteers attracted the attention from numerous media and government institutions. Their advocacy for elders constantly appealed to various stakeholders. Due to their years of support for families, the volunteers became well-known in the community. With their introduction, I was able to continue to gain access to many families in the Bund. The 38 family caregivers I interviewed were from 17 residents’ committees, each with two or three cases recommended by these volunteers.

The good rapport with both community volunteers and local residents also enabled me to have the opportunity to stay with two families, which had dementia sufferers in the summer of 2015. I lived with two host families: one patient, Ms. Zhuang, who was diagnosed with early stage dementia at the age of 69 and lived by herself; and another, the Mo family, which had a dementia sufferer in her eighties. Mrs. Mo, the daughter caregiver, happened to be the director of the residents' committee in the neighborhood. When I stayed with the Mo family, I was able to participate in some events hosted by the committee. I also talked to several other local cadres in the committee about their struggles with dementia care.

Because of my previous work experience and the rapport with various stakeholders, I was able to participate in various community events hosted by upper level government officials in the Bund and the Huangpu District. Local NGOs, entrepreneurs, and government officials often hosted regular meetings to discuss social services for seniors, and dementia care was one key topic that was mentioned constantly by some stakeholders. On account of these connections, I was able to attend several small scale meetings about eldercare. At these meetings, I was able to talk to upper-level government officials about their perceptions of dementia care.

During my fieldwork in 2017, two municipal events were related to dementia care. One—hosted by local NGOs—was the release of the documentary film *Please Remember Me* (Zhao 2017) and the associated discussion about social support for elders with dementia (see Chapter 2). During this meeting, I was able to interview three advocates for better dementia care in Shanghai: the director of the documentary film, Ms. Zhao Qing; Dr. Liu, a professor from a local university; and the director of the eldercare department from Civil Affairs, Mr. Chen. The other was hosted by the Shanghai Health Development Research Center and the Shanghai Medicine and Health Development Foundation. This event centered on long-term care for dementia sufferers. I attended these two meetings and had a chance to meet another municipal government official, Dr. Ding, who was in charge of the long-term care insurance for Shanghai.

Two national meetings related to dementia care also happened to take place in Shanghai in 2017. One was the national training of the person-centered care approach for about 40 nursing home directors in Shanghai and surrounding areas. This training last for four days. During this period, I was able to talk to Ms. Hong, a significant advocate for better dementia care in China. I also established a good rapport with several nursing home directors and discussed with them their practices of dementia care. After the training, I scheduled several site visits at nine nursing homes. I visited one nursing home three times, two nursing homes twice, and the others only once. During these visits, I was able to talk more about dementia care with nine nursing home directors and several nursing aides and other staff. With their introduction, I visited five community-based mini nursing homes, which were administrated by five nursing home managers I had interviewed before. The other national meeting was the Lujiazui Summit Meeting of Eldercare, in which I served as a volunteer, helping organize presenters' PPTs. I talked to two stakeholders who engaged in promoting better dementia care. One was from the municipal nursing home in Shanghai, and the other from Japan, who attended the meeting to expand his business in Shanghai. After the meeting, I further attended another two conferences hosted by Japanese entrepreneurs in Shanghai, which were about the professionalization of dementia care. During these events, I was able to interview the former director of the Shanghai Research Center on Aging and several other stakeholders, Mr. Zhou. In this process, I systematically studied the Shanghai governmental agenda regarding dementia care and the struggles and complaints of local practitioners, such as non-state actors.

Because of my connections with local NGOs, I interviewed four managers about their experiences of advocacy. When I conducted my fieldwork in Shanghai, only four NGOs were specialized in dementia care: Jian'ai, Jinmei, Ailaojiayuan, and Xintu. Two managers invited me to attend their events for family dementia caregivers, and I joined them as a participant. Another one invited me to visit their senior centers (three in total) for dementia sufferers. In addition, I served as a volunteer for Xintu—the NGO I used to work there—for three months from October to December 2016. During this period of time, I was able to visit another senior center that was sponsored by the local government. This center was a failed project, and I was unable to interview significant government officials. This was partly due to my ignorance of the severity of this issue at that time period (see Chapter 2, the *fengshui* damage), and partly due to the rejection of local government officials who did not believe that our proposals could solve the challenges facing elders.

I also purposefully selected a memory clinic in one of the Shanghai tertiary hospitals as a way to enlarge the research sample and enhance the representativeness of my findings. The memory clinic was located in a nearby community, which was about a ten-minute walk to the Bund. Within the Bund, there was a tertiary hospital and a community-based hospital. The community-based hospital did not provide dementia care services, and I had no connection with the tertiary hospital in the Bund. So, I turned to the nearby memory clinic, where I had connections, as a research site. This memory clinic was established in 1997 and had more than 400 dementia patients who visited this clinic every two weeks. There were three doctors engaged dementia study: two of them worked in the memory clinic, and the other worked specifically in the hospital ward. One part of the clinic was to conduct the memory assessment, which consisted of a list of evaluation tables, such as mini-mental state examination (MMSE), the Montreal Cognitive Assessment (MoCA), and other related scales. In addition to conducting memory assessment, I talked to family caregivers about their challenges of dementia care. The memory clinic, which opened each afternoon on Wednesday and Thursday, gave me the opportunity to talk to those who voluntarily wanted to talk to me. Basically, I could conduct one to three in-depth interviews with family caregivers and/or their kin suffering from dementia each afternoon. Each conversation lasted about 60 to 90 minutes. In those conversations, I conducted in-depth interviews.

In addition to interviewing family caregivers in the memory clinic, I joined these physicians in community-based health education activities. From May to October 2017, each community-based hospital hosted free physical examinations for seniors aged 65 and above in Shanghai. Physicians in the memory clinic took advantage of this opportunity to collaborate with eight community hospitals to collect data on the memory status of seniors. Meanwhile, they also hosted some public health education events. I participated and helped them organize these events in eight communities. At these events, I enlarged my network with physicians who were experts in dementia care in Shanghai. I conducted in-depth interviews with four medical experts, one psychiatrist, one gerontologist, one acupuncturist, and two neurologists. I also had the opportunity to attend several meetings hosted by the medical community, during which I was able to talk to two prestigious psychiatrists and one neurologist specializing in dementia care in Shanghai. Therefore, I had the opportunity to understand their perceptions about dementia care. I also interviewed the director of the pharmaceutical company, Eisai China, who had been advocating for the reconceptualization of dementia as a neurological disease and the correction of the name of dementia to reduce stigma. Luckily, I was able to talk to her several times.

In addition to participant observation and interviews, I conducted extensive archival research on aging policies and dementia care in libraries of the Shanghai Mental Health Center and Fudan University. The Shanghai Mental Health Center—one of the primary mental health centers, built in 1935—has the majority of mental health documents dating back to Republican China, including original texts and donated books on psychiatry. The Medical School of Fudan University as well as the Library of Art and Science, also have key documents related to dementia. With the support of Dr. Li Chunbo, who is the director of the Mental Health Center, I was able to gain access to significant documents (e.g., books translated by early scholars in Republican and Maoist China, national medical training textbooks, and state classification documents) in order to assess the changes in the conceptualization of dementia in China. My connections with friends and teachers in the Medical School in Fudan University, my alma mater, also enabled me to gain access to the library there to review some important documents. In addition to these two important sources of archival research, I searched online publications in Chinese related to eldercare and dementia care. I examined public debates on dementia and dementia care through websites, TV programs, newspapers, etc. These various sources of information helped me gain a comprehensive understanding of dementia and dementia care in China.

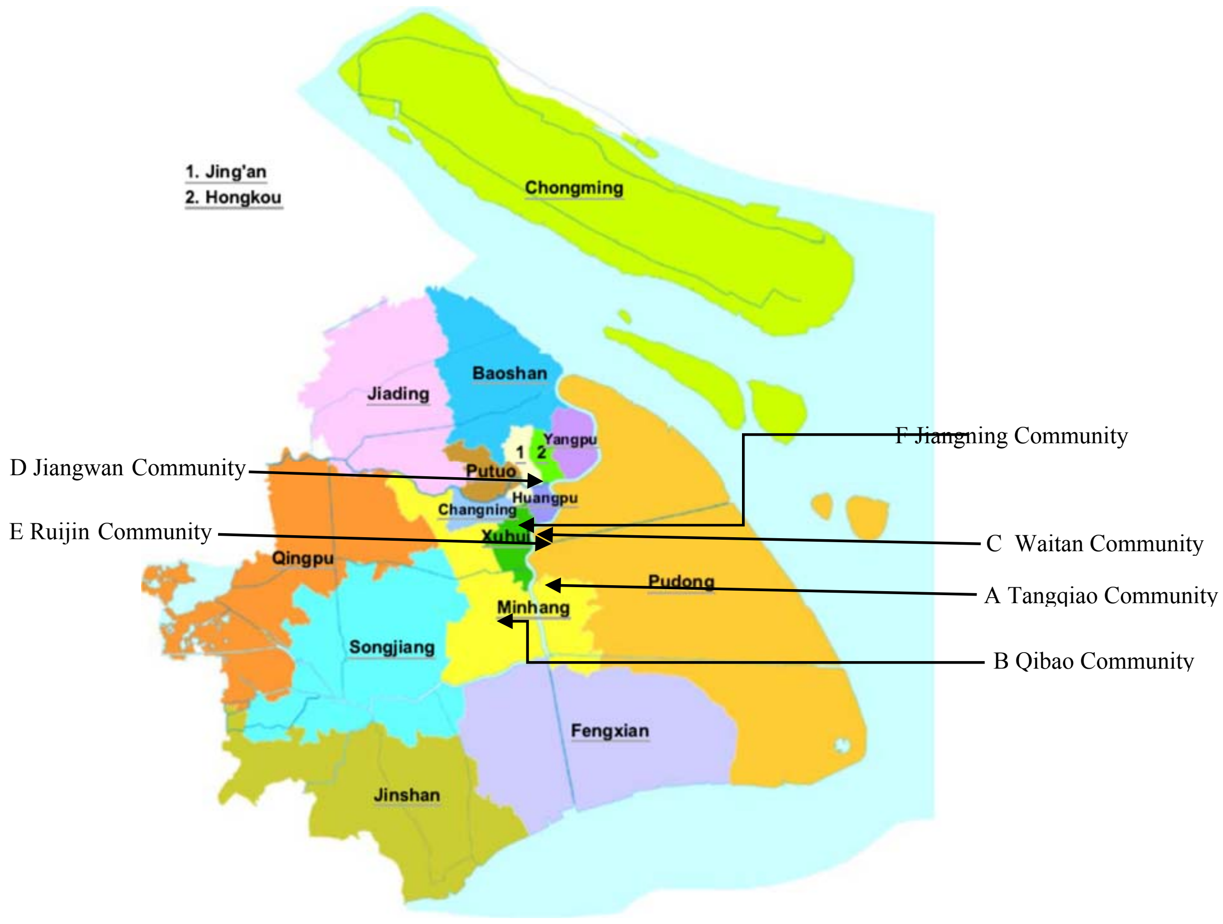

Figure 1 The Administrative Division of Shanghai (by 2018)

Outline of Chapters

My dissertation is divided into two sections: one section on biopolitical discourses and the other on experiential aspects of family dementia caregiving. The first section includes three chapters. Chapter One investigates how the state and medical professionals in China conceptualize dementia through a historical perspective, namely dementia as a vague and stigmatized condition in imperial China; dementia as biosocial deviance in Republican China; dementia as a product of capitalism during Mao-era China; and dementia as a stigmatized mental illness in contemporary China. These dynamics indicate that Chinese professionals have been largely influenced by state ideologies in assimilating biomedical concepts. Through the historical analysis of state-professional interactions in conceptualizing dementia, this chapter provides an avenue to understand how biomedical concepts transferred within the global context can be read as the site of a power struggle between ethnomedicine and biomedicine, as well as between indigenous sovereignty and modern liberal governmentality.

Chapter Two explores interactions between global humanitarian care ethics and local norms regarding dementia care. Many stakeholders in Shanghai embraced the global Dementia-Friendly Initiative, which required the establishment of dementia care units in neighborhoods. This project, however, was met with severe resistance from local residents due to its *fengshui* damage—a cultural interpretation of the loss of fortune. The study of people who advocate on behalf of dementia sufferers and their families and protests from local residents about geometric damage demonstrates how globally circulated discourses and practices of dementia-friendly ethics interact with local cultural paradigms in seeking to govern individual and collective life. By analyzing these conflicts, this chapter also reveals the workings of community-culture resistance that might undermine the efficiency sought by dementia-friendly projects.

Chapter Three examines how dementia-friendly campaigns have intensified debates about what constitutes “good” care. In response to these campaigns, the Shanghai government has proposed a systematic care model, which stresses dementia-care units and professionalization. Non-state actors, like nursing home directors, local NGO managers, and dementia-friendly advocates, however, focus on a relational care model, which integrates Western humanitarian ethics with Confucian values. Conflicts between the state’s promotion of systematic care and the endeavors of non-state actors to support relational care occur when each stakeholder enacts a specific paradigm of care. This chapter examines how cultural and structural factors shape certain forms of “good” care, and how politics—the establishment of dementia-care units and the professionalization of eldercare—shape certain forms of care.

Section Two focuses on the experiential aspects of family caregiving. Chapter Four examines the transformation of care politics from the previous patriarchal order to a negotiated egalitarian one in which obligations are balanced among adult children. That is, both adult sons and daughters equally engage in taking care of senior parents. This egalitarian family politics also fosters an emergent social norm between generations: adult-child care based on property inheritance. Senior parents and adult children often negotiate care obligations and property inheriting rights, which coexists with spousal care, hybrid forms of care, and institutional care modes. This chapter contextualizes the decision-making processes underlying care arrangements and transformations of care norms in urban China.

Chapter Five focuses on how family caregivers engage in biomedicine and gerontechnology to negotiate care outcomes. I use “care as stewardship” to draw attention to the transformed social contexts surrounding dementia care by medicine and modern technology. That is, I focus on how family caregivers interact with surrounding medical knowledge and techniques to negotiate structural and systematic care constraints. As I found in my fieldwork, gerontechnology in Shanghai today encompasses high tech for instrumental assistance, everyday tech for daily living, and home-made devices for convenience. In family settings, the tension between tradition and modernity is resolved by families emphasizing stewardship, which involves human agency, ingenuity, and morality.

Chapter Six examines the burden discourse that currently surrounds family dementia caregiving. More specifically, the legislation that requires families to take responsibility for eldercare and the medicalization of dementia that leads to stigmatization has created a form of care that I call *resigned familism*. Family caregivers who engaged in this form of care are neither fully resigned nor fully compassionate, and they often maintain ambivalent feelings about their care practices. Deriving from folk understanding of dementia, estranged families, and inadequate social support, resigned familism approaches dementia care within a burden discourse that includes a number of factors—stigma, estranged family members, and inadequate social support. Family caregivers within this care framework often find the experience of taking care of dementia sufferers to be a desperate challenge.

Chapter Seven discusses transitions of family caregiving: from solo caregivers to multiple caregivers, from home-based care to family-home aide mixed care, and eventually to institutional care. I also consider how these care transitions have been transforming the meaning of life and death. Interactions between primary caregivers and other family members and between domestic care and social support demonstrate an ongoing and dynamic experience of family caregiving. Moreover, I show how family caregivers, along with the progression of illness, reconstruct the personhood of dementia sufferers and recreate meaningful ways of life for the family and imagine meaningful death for dementia sufferers. Thus, an analysis of dementia care requires taking into account the trajectories of care, the social environment that family caregivers frequently interact with, and the transformative process in which identities, relations, and meanings of life and death are recreated.

Chapter Eight examines moral dilemmas arising from family caregiving and how family caregivers resolve these dilemmas and craft moral subjectivities by revolutionizing old forms (e.g., religious practices) and creating new forms (e.g., self-care) of morality. The family in Shanghai, as the central domain of moral life, has been constantly reconfigured to meet both social challenges and individual desires. Family caregivers employ various techniques of morality (e.g., traditional beliefs and self-care) to resolve quandaries and cultivate moral subjectivities. Stories of family caregivers illustrate that quandaries related to family life are not only related to the morally divided society (Kleinman et al. 2011), but also associated with their subjectivities. I argue that, in the face of such contradictions and discontinuities, the emergent forms of morality do not necessarily transform Chinese society from a morally divided one to an integrated one. Rather, these forms of morality should be understood as local responses to the perplexing social changes or as a way of coping with the oppressive conditions. Correspondingly, moral characters are often formed, cultivated, and negotiated at the intersections of state power, capitalist economy, family solidarity, and individual subjectivity.

Chapter 1 Governing Dementia: A Historical Investigation of the Power of States and Professionals in the Conceptualization of Dementia in China

Introduction

Older populations have been a key concern in biopolitical debates among social scientists for several decades (Bond 1992; Estes and Binney 1989; Leibing and Cohen 2006; Look 1993, 2013; Wentzell 2013). This is not only because the elderly bear upon questions of social care burdens relevant to state administration, but also because they serve as an object of professional power, particularly in the domain of global mental health. Mental health concerns an array of issues and behaviors governed—that is, made normal and pathological, valuable and vulnerable, profitable and mortal through regulatory, biomedical and political structures (Chiang 2014; Gaines 1992; Kaufman and Morgan 2005; Kleinman 1988; Kleinman and Lin 1981; Otto 2013). In the global context of population aging and extending life expectancy, aging itself has been reconstructed as a risk factor for certain mental illnesses such as dementia (Cohen 1998; Lock 2013; Traphagan 2000). This notion has challenged the dominant values and expectations of remaining energetic socially, intellectually, and physically during the process of aging (Neilson 2012).

Biomedicine is a healthcare practice through Western scientific knowledge and techniques; however, medicalization has negative consequences as well, such as potentially stigmatizing human conditions as pathological, increasing medical costs, and distorting existing ethical frames (Kaufman and Fjord 2011; de Vries, et al.1982). Michel Foucault (1976, 1987) introduced biopolitics as an approach to reflect on these and other dark sides of humanistic progress in biomedicine. Subsequent studies have revealed how modern states and medical authorities wield influence by employing biomedical knowledge in managing citizens' everyday lives (Cohen 1998; Kitanaka 2012; Leibing and Cohen 2006; Lock 2013; Traphagan 2000; Zigon 2011). These governmental processes that position life as an object of power are usually interpreted as negative, because they imply social control and externalized discipline (Borovoy and Zhang 2017). Increasingly, however, studies are demonstrating that this objectification might also be positive or productive (Farquhar and Zhang 2005; Otto 2013). Rather than using the dualistic ontologies to study connections between biopolitics and everyday practices of life, this study employs Muhle's argument that biopolitics itself *is* a form of life which "…oscillates between the biological, natural, living dimension and the permeability to an artificial, social, and material manipulation…" (Muhle 2014:92). In other words, biopolitics is a form of power which deals with the unfolding interactive experience of two poles of life: the natural life form and the social life form (Muhle 2014). Because life and power are dynamic, the articulation of life is correlated to historically-contingent techniques of power and knowledge. Instead of detaching biopolitics from the everyday practices of life, this project examines the intersection between states and professionals as well as interrelationships between various competing health professionals (i.e., psychiatrists, neurologists, and traditional medical practitioners) in producing knowledge about dementia that are taken up by many social actors.

In everyday life, examining the state-professionals' interaction is important, because it highlights the vast differences between the strategies each state has employed in governing dementia. Regarding professionals, Freidson (1986) argues that they are agents of formal knowledge who possess the power to establish a consequential relationship between formal knowledge and the everyday world. This argument is useful in this regard, because it identifies agents of knowledge, i.e., professionals, as an empirical group in terms of knowledge production, transmission, and application. Building on this argument, this study takes both biomedical and ethnomedical forms of professional power (i.e., psychiatry, neurology, and traditional Chinese medicine) into account in examining the conceptualization of dementia in China. This hybrid account is significant, because the state grants authority to each form of professionals differently with regard to the issue of knowing dementia. In hierarchical settings, one form of knowledge often gains authority, devaluing and delegitimizing others, because it is associated with a stronger power base or explains a situation better for a specific purpose (Jordan 1993). Therefore, state administrators, biomedical and ethnomedical practitioners, as well as their researchers, are each in a position to exercise different power in producing formal knowledge. Meanwhile, unlike biomedical authorities in developed countries who actively create the biomedical model for interpreting mental diseases, biomedical professionals in developing countries have primarily relied upon "imported" biomedical concepts. In this regard, anthropologists have long been interested in how cultures play a vital role when a certain biomedical concept or the authoritative knowledge either fails or successfully integrates itself into a local knowledge base. Yet, relatively little attention has been paid to how states and professionals interact with each other in adopting or disregarding the influx of certain biomedical concepts.

Focusing on the production of knowledge in conceptualizing dementia also offers a way to examine competing forms of professional powers in knowing dementia in medical-pluralist China. Different forms of professional power draw our attention because they not only involve cultural practices, but also intertwine with state ideology and public policies or strategies for governing (Andrews 2014; Gaines 1992; Phillips et al. 2013). Embodying the accumulated wisdom of a five-thousand-year-old culture, Scheid (2002) argues that traditional Chinese medicine (TCM) has been transformed into modern institutions in both training and practice in contemporary China. The development of the professional status of TCM has been significantly related to state power and state promotion of TCM (Andrews 2014; Scheid 2002; Taylor 2005), even though the current dominant medical system in China is biomedicine. Within the biomedical system, psychiatry is a form of professional power embedded in the center of both cultural practices and the overarching ideological context. For example, as mental illness is a taboo in many societies, different cultural understandings of mental illness coexist with biomedical explanations. Therefore, psychiatrists play a vital role in identifying both cultural issues and medical ones for a specific mental illness. Additionally, in order to remove cultural barriers to health-seeking, psychiatrists might need to advocate in policy-making for values that patients hold. Equally worth mentioning here is the power of neurology, which deals with symptoms originating from the brain/mind. Due to the overlap between the fields of psychiatry and neurology, knowledge from each at times competes for authoritative status in understanding dementia, even though both are equally legitimate forms of biomedical knowledge. Within the context of global transmission of medical knowledge, by investigating how local professional power reconfigures introduced Western biomedical concepts, anthropologists can answer the question: how can such an international health concept transfer be read as a site of power struggle between ethnomedicine and biomedicine, between various competing forms of health practitioners, as well as between indigenous sovereignty and modern liberal governmentality, since each of them construct different modes of social reality?

Dementia has drawn great attention from medical anthropologists because the process of medicalizing dementia, senile dementia in particular, is a biopolitical process (Cohen 1998; Lock 2013; Traphagan 2000). Aligned with genetic factors, environment factors, individual habits and physical conditions, aging itself has become a primary factor for dementia within the global context of population aging. Unlike developed countries where social support for dementia care has been developed substantially, in developing countries where there are limited resources to deal with the increasing number of elders with dementia, different states are responding differently. With the world's largest number of people with dementia, China deserves special attention not only because it is a medical-pluralist society where both traditional Chinese medicine (TCM) and biomedicine coexist, but also because of its long history of imperial bureaucracy and recent revolutionary history of Maoist socialism, as well as its indigenous political philosophy. These different ideologies adopted by the state represent different operational models for governing life and constructing dementia. How did early modern psychiatrists in Republican of China translate foreign biomedical knowledge? How was dementia conceptualized by different local medical experts from Republican of China to contemporary China? How did the state and the early Chinese medical professionals respond to biomedical concepts and findings? Particularly, how was their conceptualization of dementia crystalized into social structures of medicine and how does the mental healthcare system affect people's health-seeking behaviors? By engaging with these questions, this chapter illuminates the complex sociopolitical processes of state-professional power interaction on the conceptualization of dementia in the rapidly changing Chinese society.

Background: dementia as a vague and stigmatized condition in TCM

In imperial times, there were no serious TCM texts that specifically focused on mental illness. Dementia was the most typical symptom of "madness (*feng*, 疯)" or "insanity (*dian*, 癫)" documented by numerous Chinese medicine works. Rather than classifying these mental illnesses into an independent disease category, TCM took a somatic approach to understanding mental illness. Mind disorders such as emotional symptoms were attributed to underlying problems afflicting "organ" processes in the body. For instance, TCM viewed happiness as coupled to the heart, anger to the liver, worry to the lungs, fear to the kidneys, and desire to the spleen (notably, these pre-modern terms – heart, liver, etc. – do not map exactly onto anatomical biomedical organs) (Eisenberg and Wright 1985). This analytic approach of TCM provided a paradigm to understand dementia. In interpreting the etiology of dementia, TCM texts turned to its "material" aspects rather than "ideal" aspects. *The Complete Works of Jingyue* (*jingyue quanshu* 景岳全书) by Zhang Jingyue (1563-1640), a Ming Dynasty physician and writer, is the first TCM text to systematically introduce dementia. According to this book, emotions such as anger, frustration, over-thinking and worry, suspicion, and terror could disturb the inner circulation of *qi*,[6] resulting in too much inner fire (*huo*, 火)[7] in the heart and liver. The

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[6] Qi can be interpreted as the "life energy" within the body.

[7] Inner fire or *huo* in Chinese means the excess of energy by the overstimulation of the bodily *qi*.

imbalance of *qi* and too much fire in the heart and liver were thought to be causes for dementia. Stagnation and deficiency of *qi* and blood, deficiency of *yang*, or shortness of "a person's vital energy" or *jing* (精) in Chinese (Chiu 1986:37) were also documented as causes of dementia.

TCM texts differentiated between age-related cognitive decline and dementia symptoms. For example, *The Yellow Emperor's Canon* (*huangdi neijing*, 黄帝内经) documented dementia symptoms associated with aging, such as depression symptoms manifesting in one's sixties, and mistakes in identifying people, time, and place in their eighties (Wang et al. 1997; Zhang et al.1985). Without giving a specific name or suggesting a treatment, these symptoms were considered merely a routine part of the aging process. This notion took a deep root among the public, who considered age-related dementia symptoms to be inevitable, and thus normal. However, the *Canon* further introduced dementia conditions related to general mental disorders, such as memory deficiency and cognitive disorder. According to it, these dementia symptoms were due to too much fire inside the heart, and were treatable by herbal medicine (Wang et al. 1997; Zhang et al. 1985). It must be kept in mind that age-related dementia and dementia symptoms related to general mental disorders referred to different categories, with the former primarily referring to senile dementia and the latter to "madness" or "insanity." Age was the basic standard for distinguishing these two sets of illnesses, with senile dementia attributed to natural aging.

Regarding the terminology of dementia, unfortunately, TCM employed derogatory terms to describe dementia, resulting in stigmatization. For instance, in the Han Dynasty, in *Secret Memoir of Doctor Hua Tuo* (*huatuo shenyi mizhuan* 华佗神医秘传), the author

Hua Tuo (about AD 145 - AD 208) first named dementia as "*chi dai*" (痴呆). This term literally means stupid and retarded. These derogatory names for dementia can be found in later TCM texts. For example, in the Jin Dynasty, acupuncture therapist Huang Pumi (AD 215 – AD 282) named these symptoms as "*shi zhi*" (loss of wisdom 失智) in the famous work – *AB Canon of Acumoxa* (*zhenjiu jiayi jing* 针灸甲乙经). In the Song Dynasty, this illness was named as "*Chi*" (痴, being excessively obsessed with something; capricious and stupid[8]) by acupuncture therapist Wang Zhizhong in his work. In the Yuan Dynasty, acupuncture therapist Dou Mo (1196-1280) gave this illness the name of "*dai*" (呆, being stunned, slow minded and stupid[9]) in his book *Acupuncture Guideline* (*zhenjing zhinan* 针经指南). Rather than emphasizing the integration between body and mind, these TCM terminologies of this illness conceptualize it as solely a disease of the mind, which has entrenched its social stigmatization.

Although these aforementioned terms refer to different dementia conditions, all of them, in such a direct and derogating language, point to an obvious disorder that indicates a blatant loss of social competence. Moreover, dementia conditions – the aggressive and anti-social behaviors of persons with insanity – challenge core Confucian values such as order and harmony that are held by the society, which in turn brings extreme shame and guilt to the family. Also, Chinese cultural norms hold that the family is responsible for the individual's behavior and welfare. Thus, the burden of stigma associated with dementia tends to fall onto the family than the individual (Ramsay 2013; Traphagan

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[8] Modern Chinese Dictionary, edited by The Institute of Languages in Chinese Academy of Social Sciences, Beijing, Commercial Press, 1983, P.141.

[9] Modern Chinese Dictionary, edited by The Institute of Languages in Chinese Academy of Social Sciences, Beijing, Commercial Press, 1983, P.203.

2000). More importantly, loss of the mind also threatened the Confucian values in maintaining the family line through producing healthy male offspring (Ramsay 2008). Influenced by Taoism which emphasizes the harmonious relationship between personal life and cosmological and natural spheres, the stigma of dementia extends to both ancestors and potential future generations due to the indigenous ideas about the immortal punishment by gods (Lin 1981). Therefore, when TCM treatment was unavailable or inefficacious, the imperial state or families required physical restrictions for such patients to keep the "family face" of households (Ma 2014; Pearson 1991; Ramsay 2008 and 2013).

The cultural construction of the unworthiness of lives of such patients also affected the later development of TCM in mental illness. For example, in the Ming Dynasty, Wang Kentang (1552-1638) firstly proposed the concept of *shenzhi* (mentality 神志) in his work *Standard for Diagnosis and Treatment* (*zhengzhi zhunsheng* 证治准绳) to classify mental illness as an independent category. However, this categorization failed to impact later imperial-period TCM practitioners, indicating that mental illness was a minor strand in Chinese medical thought. Thus, personal distress associated with dementia was not historically broadly recognized clinically in TCM, which put patients with mental illness in a vicious cycle of ignorance and unworthiness, reinforced not only by the surrounding families but also by the society in large.

Dementia as biosocial deviance in Republican China

During the late Qing dynasty and Republican China, wars, widespread corruption and the encroachment of foreign exploitation forced local governments and social elites to search for ways to build a nation grounded in science and modernity. TCM, a product of imperial era, was considered backward, unscientific, and unhygienic, so it was a threat to a modern nation (Andrews 2014). Therefore, commentary on the topic of dementia by TCM dwindled in this period. On the contrary, Western ideas such as science, law, economy, and medicine, which fit into the political regime, gained great prominence. As overseas-trained scholars returned to China to perform social reforms, they also introduced modern institutions to China, including biomedicine and medical care facilities. Although medical missionaries had established medical care and psychiatry facilities in some coastal areas of China during the late Qing Dynasty (Andrews 2014; Chiang 2014; Pearson 1991), these efforts were dominated by foreigners and the political environment was too chaotic to allow these early initiatives to replace TCM. It was not until the 1930s—a period of state-building – that the nationalist government started to make substantial efforts to improve public health by establishing Chinese-dominated modern biomedical healthcare and medical training systems (Andrews 2014; Chiang 2014; Kleinman 1986). This reform made the study and practice of psychiatry possible in China.

In editing national psychiatry training textbooks, psychiatrists constantly checked abroad for validation. The Japanese influence on the development of modern Chinese psychiatry was particularly salient since most Western psychiatry training textbooks were translated into Chinese from Japanese. For example, the earliest psychiatry textbook, *Outline of Psychiatry* (Chen 1937), was primarily referenced from Japanese psychiatry. Another psychiatrist and physician was Sheng Peicong (盛佩葱), who also got medical training in Japan and later returned China for practice. However, the Sino-Japanese war from 1937 to 1945 shifted the attention of the Chinese medical community to American psychiatry for reference. The famous Chinese psychiatrist Dr. Su Zonghua (粟宗华) got his medical training in the U.S.A. and later went back to China to practice. He was also the first professional editor of China's psychiatry training book to use cases collected in his clinical practice. By examining their works, we can trace changes in the conceptualization of dementia in Republican China.

The first change in understanding dementia was the shifting emphasis from the body/heart to mind/brain. Dementia, like other psychiatric symptoms, e.g., disorders of consciousness, perceptions, thinking, etc., aim to be seen as a mental illness related to the mind/brain rather than the body/heart. In order to differentiate mind from body, Su Zonghua and Tao Juyin, called upon a metaphor in their collaborative work *Outline of Psychiatry* (1951). They referred to the relationship between body and mind as the relationship between a modern city and electricity. The body needs the mind is just like a modern city requires electricity to maintain basic daily functions of production. Sufficient "electricity," or mental energy, maintains basic production needs of a modern city, i.e., the body. Either high or low "electricity" results in too much or insufficient production of a modern city, therefore, mental abnormalities. Moreover, Su and Tao laid out the division between mental disorders and neurological disorders following this metaphor. When "electricity" is delivered to different parts of the city, it is the "electricity transportation system," i.e., the neurological system, which includes brain, spinal neurons and peripheral neurons that take charge of distribution. Su and Tao referred to brain as the "engine," spinal neurons as the main wire, and peripheral neurons as the branch wire. Since "electricity" is delivered by the "transportation system," the breakdown of each section of the “transportation system” leads to insufficient “electricity” for “the city sector,” in accordance with the demonstrated mental symptoms in some neurological disorders. However, insufficient electricity (mental dysfunction) of the city (the body) could also result from limited materials for the engine (the brain) to produce electricity. This metaphor not only corresponds to the local social reality of building a modern nation, but it also reduces mental illness into a dichotomous ontology, i.e., positioning the mind as opposite of the body. Clearly, compared to vague notions of TCM, the biomedical paradigm of psychiatry is much easier to locate causes of illness of the mind/brain, therefore, establishing its epistemological authority in interpreting dementia.

Age still plays a significant role in medicalizing and classifying subtypes of dementia in Republican China. The conviction that old age was inseparable from mental failure continued to dominate the medical community during this period. Cognitive decline in an advanced age, especially in one’s 80s, was interpreted as a routine part of the aging process, just as TCM dealt with it. This was due to the notion that aging itself was accompanied by changes in the balance between body and mind. Thus, senile dementia was an inevitable consequence of aging. Through examining the classification of mental disorders during this period, psychiatrists mentioned senile dementia with old age, but there was no statement of old age under sections on insanity – insanity referring to any mental conditions including dementia. However, dementia condition at an early onset was dealt with differently. For instance, dementia in one’s 50s was highly considered as Alzheimer’s disease. Similarly, dementia praecox happened between 17 and 25 years or older. There were also dementia conditions found at six or older such as the oligophrenie disease entity, which was due to endogenic deficiency or neurodevelopment dysfunctions. Although psychiatrists had introduced some pathological changes to distinguish these dementias (Su and Tao 1951), clinical diagnosis primarily relied on presentations of dementia symptoms. However, symptoms such as failure of memory, disorientation and confusion were too general among subtypes of dementia (e.g., dementia praecox, dementia paranoids, and Alzheimer's disease). With limited biotechniques, psychiatrists in Republican China dealt with classification of dementia primarily based on age of onset. Although age was useful to distinguish senile dementia from other cognitive disorders, it actually contributed to the establishment of age-related cognitive decline as a unique disease entity, which provided later impetus to reevaluate ideas concerning senility.

Although psychiatrists considered senile dementia as an inevitable feature of advanced age, especially in one's 80s, they had an upwelling of interest in introducing other dementias based on etiology. Attention was first paid to paralytic dementia because of high incidents of sexually transmitted diseases in late Qing and Republican China (Chen et al. 2013; Cohen et al. 1996; Lennox 1923). From the biomedical standpoint, neuro syphilitic infection could result in a reduction in the diameter of both the peripheral and cerebral blood vasculature, which further caused neuro cell death accompanying with dementia conditions (Berchtold and Cotman 1998). This pathology theory that vascular disease was a predominant cause of dementia also applied to other social causes of dementia, such as alcohol or drug abuse (Chen 1937; Sheng 1951; Su and Tao 1951). Although psychiatrists introduced these types of dementia primarily based on referring to foreign textbooks translated from Japanese, the reality that lack of social order to control social deviants and the absence of a scientific understanding of these human conditions in

Republican China also compelled them to pathologize these social phenomena. In an era when only limited medication could be provided, the result of medicalizing these social conditions fit quite well into the political framework, i.e., to build a modern nation with science, while its clinical efficacy was not important.

Although medicalizing the mind in Republican China had more political significance than clinical effects, I have to note that psychiatry was a minor strand in the biomedical training curriculum. Due to culturally rooted discrimination toward mental illness, psychiatry was misunderstood not only by social elites, but also by other biomedicine practitioners. They considered psychiatric disorders as "invalid, vague, mysterious, idealistic, and cannot be understood and cured" (Su and Tao 1951:3). Because of this cultural bias and misunderstanding, some medical schools did not even provide psychiatry training or just merged it with internal medicine (Sheng 1951; Su and Tao 1951). Equally worth mentioning was that, unlike the TCM explanatory model to somatize dementia, psychiatry de-somatized dementia by refining it with the categorization of different conditions in which dementia was found. This action should, and also could, have de-stigmatized dementia conditions; however, early psychiatrists continued using the previous derogatory terms to name dementia. Even in some early psychiatric texts, people with dementia were considered as "living dead" or "walking dead" (Su and Tao 1951:236). Thus, social discrimination for people with dementia not only existed as a cultural reality at the grassroots, but was also evinced by the psychological logic that defined normal and pathological by medical authorities. The limited vision of dementia classification, the failure to find a specific non-derogatory terminology for dementia, as well as the ignorance of the stigmatizing effects of medicalizing dementia, all contributed to severe social negativity about dementia conditions.

Dementia as a “product of capitalism” in Mao-era China

On Oct 1st, 1949, the People’s Republic of China (PRC) replaced the Republic of China, taking over the administration of the state. Coupled with the shift in the state ideology came a transformation in the interpretation of mental disorders. The Chinese Communist Party (CCP) developed a deep distrust of foreign powers, and was especially distrustful of Japanese and American psychiatry due to the past century’s nationwide instability and insecurity born of Western imperialism and Japanese invasion in China. Because of this deep distrust, the CCP turned to follow Soviet psychiatry for reference. The Soviet paradigm pursued Marx’s dialectical materialism and resisted idealism in interpreting mental disorders (Shi and Sun 1960), fiing into the Chinese state ideology. Instead of pursuing biological understanding of human diseases, the CCP followed the Soviet path— focusing on the political nature – of illness (Munro 2006). For example, the first National Conference on Health held by the Ministry of Health in August of 1950 established three political principles in guiding the public health under the CCP, including serving the interests of workers, peasants, and soldiers, prevention first, and integrating TCM with Western medicine. Moreover, this conference proposed guidelines for editing medical training textbooks, i.e., to carry out the new communist mass education policy, suitable for the needs of common person, and to put communist theory into practice (Wang and Cao 1953). With these policies, the scope of intellectual freedom was significantly narrowed in pursuit of ideological reform. The development of Chinese psychiatry from the 1950s to the 1970s situated within this distinctive historical discourse.

Chinese psychiatry was developed in the shadow of Soviet influence. Due to the same Communist camp, frequent exchanges between the PRC and the Soviet Union in the field of psychiatry in early 1950s brought China not only Soviet psychiatric texts but also training opportunities for local psychiatrists (Shi and Sun 1960). This was profoundly important since the first cohort of psychiatrists in the PRC developed their conceptualization of mental disorders based on the Soviet paradigm. For example, Soviet psychiatry at this time was dominated by Pavlovian theory, which emphasized connections between psychiatry and physiology. Chinese psychiatrists endorsed Pavlov's higher nervous system activity as a scientific foundation for locating the brain psychiatric or nervous system as the root cause of mental disorders. Correspondingly, in the first edition of the national textbook in Maoist China, Chinese psychiatrists put psychiatry and neurology together into one national medical training textbook *Neurology and Psychiatry* (Wang and Cao 1953). Another fact emphasizing the understanding of mental illness from the stand of point of neurology was the clinical journal *Chinese Journal of Neurology and Psychiatry* founded in 1955.

The mental health care system was also subject to the revolutionary purpose of the state. In 1958, the state held the first National Conference on Prevention and Treatment of Mental Disorders in Nanjing, which established the mental health care system (He 1958).[10] As He wrote, during this conference, government officials and medical

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[10] The mental healthcare system has been separated from the general healthcare system in China ever since 1958.

authorities considered mentally ill patients as victims of capitalist societies or remnants of the "old society" characterized by a feudal social system. As a communist country equipped with a "higher and better" social system, officials in China argued that health practitioners should abandon the bourgeois theory of "mechanics" in dealing with mental disorders, which narrowly focused on diseases rather than on patients' needs. Thus, the new mental health system should target patients' physical and psychological needs to improve their quality of life. In practice, this conference suggested four basic state treatments for mentally ill patients, including the integration of TCM and Western biomedicine to improve physical conditions; physical exercise and art therapy; work therapy involving rehabilitation through labor; and ideological re-education to equip these patients with communist thoughts. Structurally, the state established three forms of organizations (e.g., medical facilities, prevention units, and nursing homes) to facilitate the reformation of mentally ill patients. Moreover, there were numerous of workshops (e.g., farming, nurturing forest, knitting bags, repairing shoes, etc.) in both rural and urban areas to assimilate mentally ill patients into social production activities. Although this mental health system was effective in decreasing incidence of relapse and minimizing health cost on the state by providing work opportunities for the mentally ill (Park et al. 2005; Shen and Li 1978; WHO and ILO 2000), its political nature drew debate for the potentiality of misusing psychiatry for political purposes (Lee and Kleinman 2002; Munro 2006).

Dementia was redefined as a product of capitalism to serve the interests of the political system. During the National Conference on mental health in 1958, the state and psychiatrists proposed fourteen categories of mental disorders. The categories and criteria for evaluating dementia which had applied in Republican China were no longer applicable in Mao-era China. Regarding dementia, Chinese state and medical authorities classified pre-senile and senile mental disorders as one disease entity, regardless of patient age. They considered that mental disorder was highly related to problems within the social system. For example, in a capitalist society such as America, the prevalence of mental disorders among elderly people was reported to be 25-30% with an annually increasing trend (Mayer-Gross et al. 1963). However, based on the statistics of Nanjing Mental Disorder Prevention and Treatment Center, the Chinese prevalence was only 0.41%. Researchers argued that characteristics of communist society such as labor habits and social respect for elders contributed to this low prevalence (Shi and Sun 1960). These researchers believed social distress was also a cause for mental disorders such as dementia (Mayer-Gross, et al., 1963). Loss of close family members, insecure income, neglect of elders by children, and detachment from society were said to be social stressors that could lead to dementia. Such social stressors were seen as mainly features of capitalist societies. Due to the low incidence of dementia in the 1950s' China, psychiatrists did not even consider dementia as an important topic in the medical training textbook *Neurology and Psychiatry* (Wang and Cao 1953). This was very likely related to low recognition and low motivation to find or report dementia during that era, as well as the low number of elderly in the population at that time.

The Sino-Soviet split in the late 1950s and early 1960s affected the further development of Chinese psychiatry. In 1960, both neurology and psychiatry constructed training textbooks independent of Soviet Union. While neurologists for some reasons excluded dementia as a neurological disease (Zhang 1960), psychiatrists elaborated on previous writing about dementia (Shi and Sun 1960). Without the Soviet Union's support, Chinese psychiatrists shifted their attention to British psychiatry's approach to understanding mental disorders. Their primary work was the translation of the first and second editions of *Clinical Psychiatry* edited by W. Mayer-Gross, E. Slator and M. Roth (1963). In this translated book, age was brought back in, and dementia was sub-categorized as middle-aged dementia, senile dementia, and secondary dementia due to brain damage. According to this classification, dementia at 60 or above was a mental disorder subsumed to senile dementia or secondary dementia based on its observed etiology. This classification has influenced later interpretations of dementia by Chinese psychiatrists. For example, psychiatrists of Nanjing Mental Disorder Prevention and Treatment Center articulated that senile dementia, which usually started between 65 and 75, was to be categorized as a form of senile psychosis (Shi and Sun 1960). In *Psychiatry,* edited by Liu Changyong (1964), senile dementia was classified as organic lesion disease which characterized not only senile symptoms but also personality changes. Yet, unlike psychiatry textbooks in Republican China, references in this epoch did not mention whether it was normal for senile dementia to occur at the age of 80 or above. This was probably due to the fierce Western debate about whether or not Alzheimer's disease was unique from senile dementia (Berchtold and Cotman 1998). Thus, Chinese psychiatrists conservatively dealt with Alzheimer's disease and senile dementia as two disease entities. While senile dementia was classified as simple senile psychosis, Alzheimer's disease with an onset age of 40 or even earlier was categorized as pre-senile dementia (Liu 1964). This broad classification skillfully laid itself in the middle ground between the previous political understanding that dementia was a bourgeois' product and the novel biomedical understanding of Alzheimer's as a disease.

Traditional Chinese medicine gained significant support from the state to fit the political cause of promoting Chinese cultural nationalism. State policies such as the integration of Chinese and Western medicines, the institutionalization of TCM in 1950s (e.g., the establishment of Research Academy of Traditional Chinese Medicine in 1955), and the standardization of TCM training textbooks in 1960 (Andrews 2014; Taylor 2005) contributed to the development of TCM. Yet, in harsh social and political conditions where there were limited material supplies, the development of TCM was not only to cater to practical health needs, but also to assist the political revolution. Like communist psychiatry, TCM was used much more as a political tool to correct the bourgeois thought of doctors of Western medicine than as an independent, scientific discipline to explore its therapeutic value. Therefore, the aim of incorporating TCM into the mental health care system was to create a new medical system to serve the nation's revolutionary plan to support communist rule. Under such a political circumstance, the development of TCM was limited to the standardization of knowledge and its academic value in treating mental illness had not been fully understood. The status of TCM remained peripheral in understanding and treating mental illness. In the first and second editions of TCM training textbooks during the Maoist China, mental illness was merged into Internal Medicine of TCM, rather than being presented as an independent subject (Taylor 2005). Even though TCM was close to state power, TCM was dependent on the interests of political system that supported it. Without a crucial attention from the state, the understanding of dementia in TCM did not advance beyond what it had been in imperial China.

The Cultural Revolution took place from the year 1966 to 1976. During this time medical schools shut down and publications stopped. Although there was very limited progress in the academic field of psychology or neurology during this period, the newly-established PRC mental healthcare system had a profound effect of integrating the mentally ill into social production of activities. This system should have shifted the politics in understanding of mental illness in China. Unfortunately, the positive effect of this ideological reform was proved to be little more than an ephemeral blip, since politically correct thought overarched the practical value and medical efficacy in dealing with patients with mental illness. Moreover, the state labelled these patients as political deviants in need of ideological reform, which aggravated existing cultural stigma on behavioral health issues. Although individuals with dementia avoided political attacks during these chaotic years due to its "low" prevalence, the conceptualization of dementia as a "product of capitalism" emphasized political circumstances rather than biological standard.

Dementia as a biological but stigmatized mental disorder in the CCMD

After the Cultural Revolution, the state initiated a series of social and economic reforms to improve social efficiency and productivity, mental healthcare included. Over the next several decades, attention in the psychiatry field was focused in particular on developing the Chinese classification and diagnostic criteria for mental disorders. In 1978, the second National Conference on Neurology and Psychiatry was held in Nanjing. In this conference, Chinese biomedical professionals proposed the trial draft of the Chinese

Classification of Mental Disorders (CCMD), which was later published in the *Chinese Journal of Neurology and Psychiatry* in 1979. Inspired by the third edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-III), a publication of the American Psychiatric Association, Chinese biomedical professionals revised the trial draft of CCMD several times from 1981 to 1985 and finalized the first version of CCMD (CCMD-1) in 1985. Unlike the 1958 classification system, in which dementia was categorized as “pre-senile and senile psychosis,” in CCMD-1, dementia – still bearing the label of “pre-senile and senile psychosis”—was subsumed under the category of “organic mental disorders in the brain” (Beijing Medical College 1980). Ostensibly, this classification was based on etiology because it located causes of dementia in the brain. However, this category was subdivided according to age of onset, with senile dementia continuously categorized as simple senile psychosis. Alzheimer’s disease – considered pre-senile dementia in 1958’s classification – was labeled as “atypical senile dementia” in CCMD-1 due to similarities with senile dementia in clinical and psychopathological presentations but with different ages of onset. That is, senile dementia was seen as occurring at the age of 60 or above, and AD as occurring below the age of 60.

Changes in conceptualizing dementia were ongoing in later versions of CCMD. In 1989, Chinese Neurology and Psychiatry Association and the Mental Health Research Center in Hunan Medical College together published the CCMD-2, in which Alzheimer’s disease and senile dementia became one disease entity for the first time in China. Coupled with the pre-senile dementia, senile dementia became a subtype of Alzheimer’s disease (Shen 1989). Similarly, in 1995, the Chinese Psychiatry Association and Nanjing Medical

College together published a revised version of CCMD-2 (CCMD-2R).[11] The category of Alzheimer's disease expanded into four subtypes, including pre-senile dementia, senile dementia, atypical or mixed type, and other types" (CPA and Nanjing Medical College 1995; Shen 1995). Unlike the CCMD-1, in which the age of onset was used to distinguish senile dementia and Alzheimer's disease, in both the CCMD-2 and CCMD-2R, Alzheimer's disease encompassed senile dementia, primarily due to similar clinical changes. In 2001, Chinese Psychiatry Association published CCMD-3 and noticeable changes were made to align itself with international standards (CPA 2001; Hao 2001 and 2004; Lee 2001). One of these changes was that Chinese psychiatrists adopted the coding system (F00 - F99) of the World Health Organization's (WHO) International Classification of Diseases-10 (ICD-10).[12] Thus, since CCMD-3, Alzheimer's disease was coded as F00, which included pre-senile type (F00.1), senile type (F00.2), atypical type or mixed type (F00.3), as well as other types of Alzheimer's disease or unspecified (F00.9).

If different versions of CCMD represent an attempt at global standardization with local diagnostic features, the later disappearance of discrepancies between local diagnostic standards and those of the international categories indicates a remarkable unification with WHO's global system. For instance, in the sixth edition *Psychiatry* (Hao 2008), Chinese psychiatrists announced that the psychiatry training textbook completely followed the ICD-10 on the classification and diagnostic criteria of mental disorders to facilitate clinic

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[11] Chinese Neurologic and Psychiatric Association was established in 1951 and divided into Chinese Neurologic Association and Chinese Psychiatric Association in 1994. While Chinese Journal of Neurology and Psychiatry was founded in 1955 and divided into Chinese Journal of Neurology and Chinese Journal of Psychiatry in 1996. Since then, each discipline established its own medical community.

[12] From 1978 to 1994, different versions of CCMD used the Chinese classification codes of mental disorders (00-99).

diagnosis, research, medical training, and disease administration. Moreover, in the seventh edition *Psychiatry* (Hao and Yu 2013), the Ministry of Health declared that the Chinese state adopted the ICD-10 standard for mental health administration. Meanwhile, in the chapter Classification and Diagnostic Criteria of Mental Disorders, both ICD-11 and DSM-V are briefly introduced, indicating that China is no exception in following the global system of psychiatric classification.[13] Unlike psychiatrists in Mao-era China who had been trained by the rigid Soviet paradigm and cautious in adopting Western concepts, Chinese psychiatrists in the reform era (1978-present) have rapidly adopted these international standards for diagnosing mental disorders, reflecting China's openness to the global flow of medical information and technology.

The rapid globalized medicalization of senile dementia as a mental disorder in contemporary China does not imply a stigma-free social context for dementia there. The previous sections analyzing the stigma associated with dementia have shown that there are cultural, social, and political undesirabilities characterizing such a condition whose hereditary potential has long been recognized by the general public. The recent biomedicalization of dementia, evinced by all editions of psychiatry textbooks since 1980, emphasizes the genetic deficiency of those with dementia, such as a higher incidence of Alzheimer's disease within a family. Such an illustration legitimizes this biomedical explanatory model, but also, amplifies the genetic potential for dementia. The genetic association with dementia overlaps with the folk understanding of mental illness in China. Therefore, previous cultural protections for seniors who suffered from

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[13] Although ICD-11 and DSM-V are available, ICD-10/CCMD-3 remains the official standard of Judicial Psychiatry in China.

dementia, namely the expectation of memory loss at the late life stage and of childish behavior at an advanced age (Ikels 1998), have been vaporized in the face of biomedical standards for evaluating an aging person. As a result, the medicalization of dementia reinforces the stigma in China. Moreover, although professionals emphasize the fact that there are a variety of underlying etiologies for dementia, the afflictions of the mind and behavior caused by dementia – e.g., faltering memory and reasoning, socially disruptive behavior and incontinence – are too apparent to the public. This is primarily due to the overwhelming negative public portrayal of dementia circulated by the media and in brochures used by public health authorities (Ramsay 2008 and 2013). The increased public awareness of the mind constituting a key concern in maintaining high quality of life in contemporary China also reinforces the persistence of stigma in the public. In memory clinics or other public settings, stigma manifests itself in a form of silencing, indifference or ignorance. People never opening talk about it. Lastly, medicalizing senile dementia as Alzheimer's disease does not remove it from the catchall pejorative disease category of "*chidai* (dementia, 痴呆)." For example, in CCMD-3 and in psychiatry training textbooks, each subtype of Alzheimer's disease still bears a suffix of "*chidai* (dementia, 痴呆)," which underpins the existing stigma. Coincidentally, in the Chinese ICD-10, the term of "*zhang ai* (disorder, 障碍)" to name mental and behavioral illnesses was translated into "*chidai* (dementia, 痴呆)" based on traditional understanding, worth little effort to find a complementary word for this condition. Even Alzheimer's disease was translated into "*a er cai mo shi bingxing chidai* (dementia due to Alzheimer's disease, 阿尔采末式病性痴呆)" in the official translations of ICD-10 (WHO 1993).

Negotiating the representative authority in dementia care in medical-pluralist China

In 2017, the Catalog of Basic Drugs Covered by State Health Insurance was released. According to this catalog, medicines for dementia treatment such as Donepezil, Memantine, and Rivastigmine are restricted to neurological specialists, which means that only neurologists can prescribe these drugs for dementia treatment. How have neurologists become the primary representative authorities in dementia treatment? How do Chinese psychiatrists and TCM practitioners respond to the authority of dementia care being amended to neurologists? This section introduces how different healthcare professionals negotiate their valuable authority in dementia care in China.

Neurologists: establishing their authority in dementia care

While Chinese psychiatrists were focusing on the improvement of CCMD with international standards, Chinese neurologists had an increasing interest in dementia conditions. In early medical training textbooks from 1960 to 1987, dementia was excluded from the neurology textbooks because it was considered a mental disorder (Huang 1984; Zhang 1960). However, between 1991 and 1996, both the second and the third editions of the textbook *Neurology* (Hou 1996; Huang 1991) included Alzheimer's disease, and categorized it as a neuro-degenerative disease. The ensuing progress of medical technology in identifying different causes of dementia further transformed the conceptualization of this human condition. For instance, the fourth and fifth editions of *Neurology* (Wang 2001; Wang and Luo 2007) gave a clear description of the genetic risk of Alzheimer's disease, including the APP, PS1, PS2, and ApoE. Moreover, *Dementia* – replacing the previous "*Neuro-degenerative disease*" – was titled as an independent chapter to bridge various etiologies of each subtypes. Alzheimer's disease, Pick's disease, frontotemporal dementia, Lewy body dementia, and vascular dementia were all included in chapter *Dementia*. This modification might be pragmatic in professional training. However, Chinese neurologists – as psychiatrists had done – overemphasized the symptomatology (e.g., the cognitive impairment) and employed a derogatory term to encompass these illness conditions. As a result, Chinese medical professionals consciously labelled it as a stigmatized disease in the national medical training textbooks. Neurologists' reconceptualization of dementia by using stigmatized terms serves not only as a telling instance of extreme stigma, but also as a reverse mirror for us to examine how Chinese medical professionals selectively disregard the humanistic dimension of biomedical concepts.

In the later sixth and seventh editions of *Neurology* (Jia and Chen 2016; Jia et al. 2010), the chapter *Dementia* was changed back to the previous title "*Neuro-degenerative diseases*." Vascular dementia was moved to the chapter "*Cerebrovascular disease*." Moreover, detailed descriptions of dementia and its subtypes as well as its potential treatments were elaborated by referring to the most recent international studies in this field. For example, in these textbooks, concepts such as pre-mild cognitive impairment (pre-MCI), mild cognitive impairment (MCI) and vascular cognitive impairment no dementia (VCIND) were introduced to expand the scope of dementia conditions. Yet, terminologies of dementia and its subtypes remained the same as previous editions, indicating a continuing stigma of these diseases. Regarding the diagnosis, unlike the psychiatry textbooks, which primarily referred to CCMD or ICD-10, neurology textbooks turned to American standard in diagnosis, such as DSM-IV or NINCDS-ADRDA.[14]

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[14] NINCDS-ADRDA refers to National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Diseases and Related Disorders Associations.

Although the previous ICD-10 versus DSM-IV have a lot in common in disease diagnosis and classification, differences in the latest version of ICD-11 and DSM-V (APA 2014) seem to impede not only the international communication and research, but also local communications between two important domains in dementia studies in China.

Three factors have contributed to the above transformation in understanding of dementia in China. First, the remarkable progress of medical technology has visualized the neuropathological changes, such as brain atrophy, senile plagues, and neurofibrillary tangles, which has legitimized the classification of dementia as a neurological disease even though it has some psychiatric symptoms. Someone might note that these changes were also documented in previous psychiatric training textbooks, however, the then-resources for knowing dementia were primarily translated knowledge from abroad rather than Chinese researchers' own efforts. With the aid of medical technology, Chinese neurologists can establish their own understanding of dementia in both research and diagnosis. Second, neurologists' interest in dementia was subject to the changing demands of society, such as the increasing number of elders with dementia in China. Compared to the relatively low incidence of dementia during Maoist China, the number of elders with dementia in 1990 (Zhang et al. 1990) was 3.68 million, and 9.19 million in 2010 (Chan et al. 2013), with a trend of continuing increase as the population aging. Lastly, the advent of drugs to treat dementia conditions, such as *Oxiracetam* in 1988 and *Donepezil* (also known as *Aricept*) in 1996, and their availability in Chinese market also forced the Chinese state and medical authorities to reevaluate dementia and its social impact. Substantial efforts had been made to facilitate the development of dementia research in China, including the establishment of Alzheimer's Disease Chinese (ADC)[15] in 1998 and increasing funding resources from state and private sectors (primarily domestic and international pharmaceutical companies). During these medical and social transformations, neurologists have actively engaged in dementia research through institutional collaborations and personal endeavors, and thereby established their authority in dementia care.

Chinese neurologists established their authority in dementia care also through structural modification within hospitals. In order to encourage patients to seek dementia care and facilitate this process, many neurology departments in general hospitals, especially tertiary hospitals, have founded memory clinics since 1990s.[16] These clinics were initially focusing on research, but later with the introduction of potential treatment for dementia, they started to provide examination, diagnosis, prescription and medical consultation. For example, one of the most famous memory clinics in China is located in Shanghai Huashan Hospital, where Dr. Guo Qihao, a neurologist, specializes in dementia diagnosis and treatment.[17] Currently there are more than one hundred memory clinics in China.[18] But these memory clinics are limited to top hospitals. In order to promote diagnosis of dementia, neurology departments in tertiary hospitals play a vital role. Some memory clinics or neurology departments also perform public health education on dementia, such

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[15] Alzheimer's Disease Chinese is a non-profit, non-governmental organization in China, which is the official member of Alzheimer's Disease International.

[16] Personal communication with Dr. Zhang Mingyuan, a well-known Chinese psychiatrist in dementia studies.

[17] Notably, Dr. Guo Qihao majored in psychiatry, focusing on dementia studies first. It was not until 1998 that he led the memory clinic in Huashan Hospital and then became a well-known neurologist specialized in dementia.

[18] Based on the report from the national program *Yellow Hand Ring*, there were 81 memory clinics nationwide in 2017. However, this number is not quite true since there are about more than 20 memory clinics in Shanghai based on the first author's observation. However, *Yellow Hand Ring* only reported four hospitals that equipped with memory clinics.

as introducing basic knowledge and prevention strategies to communities. Yet, compared to the number of memory clinics and neurology departments in general hospitals, the number of mental hospitals which can provide dementia care is much less.

As discussed above, dementia has been medicalized as a stigmatized mental disorder in China; to avoid stigma is another impetus for patients and their families to seek neurological care. Although modern medical technologies have unveiled some of the underlying causes of dementia, classifying dementia as a mental disorder still has a profound socio-psychological effects in driving patients and their families away from mental health care facilities. Moreover, the diagnosis with a derogatory term only aggravates the stigma by depriving the dignity and social being of patients. However, in neurology departments or memory clinics, memory problems are easier for patients and families to accept than mental disorders in mental health centers. Patients seeking healthcare from memory clinics or neurology departments intend to distinguish their conditions from severe dementia conditions or mental disorders, even though some patients or families were consciously aware that their illnesses might be related to dementia. Several recent medical terms such as pre-MCI, MCI, or official terms such as cerebral infarction, or the Chinese translation of Alzheimer’s disease (*a er cai hai mo bing*, 阿尔采海默病) symbolize less stigmatized identities. Unlike mental disorders, these new medical terms related to dementia in memory clinics or neurology departments provide a safe zone for patients and families to negotiate a social identity.

TCM practitioners: the hope to cure dementia

TCM has drawn plenty of attention from all of the world ever since 1971 when the New York Times columnist James Reston underwent an appendectomy with acupuncture anesthesia while he accompanied the Nixon entourage to Beijing. Yet, it was not until the reform era that the scientific merits of TCM are recognized by the Chinese state and biomedical authorities. This is evidenced by the increasing efforts from both domestic and international agencies devoted to TCM research and practice. For instance, WHO actively supported the research of TCM on its therapeutic mechanisms by collaborating with local colleges of TCM in China, such as the establishment of the World Federation of Acupuncture and Moxibustion Societies in Beijing in 1987 (Scheid 2002). Meanwhile, realizing that TCM could be a national representative ambassador for China, Chinese state officials and TCM practitioners also actively promote TCM in the global community, such as in China's Anti-Malaria campaign in some countries of Africa (Hsu 2009; Li 2011).

Growing global recognition of the scientific value of TCM has facilitated the later development of TCM in dementia research. Despite modern biomedicine's incredible innovation and resulting accumulation of valuable knowledge, effective cures and treatments for Alzheimer's disease are still limited. As the need for novel and effective treatments increases, researchers worldwide have turned to traditional medicine as a resource. One of the significant TCM drugs for dementia treatment is *Huperzine A*. This medicine was extracted from the Huperzia serrata Trev. and other Huperzia species in 1986 by Chinese scientists (Liu et al. 1986; Ye and Zhang 2012; Zhang et al. 2002; Zheng and Su 2008). It is a reversible acetylcholinesterase inhibitor (AchE) and N-methyl-D-aspartate (NMDA) receptor antagonist that can cross the blood-brain barrier and with limited side effects. Since *Huperzine A* was introduced in the market in 1994, Chinese doctors have used it for a possible treatment for neurodegenerative diseases such as Alzheimer's disease (Zheng and Su 2008). This outcome has inspired hundreds of TCM practitioners to keep exploring in this field, including acupuncture therapists' efforts to figure out possible solutions by searching ancient TCM textbooks (Lu et al. 2003; Tian et al., 2001; Wang et al. 2007). Although *Huperzine A* marked significant progress in Chinese exploration in dementia care, the TCM pharmaceuticals have taken only a minor portion in the market, when compared to the increasing number of Western pharmaceuticals that flooded into China.

Another breakthrough of TCM in dementia care is the official inclusion of *dementia* as an independent disease entity in the 1997 national edition of TCM training textbooks. In previous editions of TCM training textbooks, symptoms of dementia were subcategorized into two Chinese disease entities, including *jianwang* (memory loss, 健忘), and *diankuang* (madness, 癫狂) (Zhang et al. 1985). *Jianwang* primarily refers to memory loss, i.e., early stages of dementia, and *diankuang* represents the severe psychiatric symptoms of dementia. It was not until 1997 that *chidai* (dementia,痴呆) appeared in the national TCM training textbook as an independent disease entity, almost paralleling with the aforementioned outcomes in TCM research ondementia during 1990s and 2000s. In this national textbook, together with *jiangwang* and *diankuang, chidai* was classified as a subcategory of heart and brain diseases (Wang et al. 1997). This classification indicates that *chidai* differs from *jianwang* and *diankuang* due to its unique characteristics. First, it is age-associated, i.e., the prevalence of *Dementia* is higher among older ones than younger ones. Second, although there is some overlap on symptoms of *jianwang*, *chidai*, and *diankuang*, *chidai* differs from the other two in terms of its progressively memory loss, personality changes, and functional ability loss. Third, the underlying etiology is also different among the three diseases. According to TCM perspective, *chidai* is primarily due to depletion of *qi* and blood as well as phlegm turbidity, blood stagnation, and *qi* depression, while *jianwang* is primarily due to depletion of *qi* or blood, and *diankuang* primarily due to phlegm turbidity, blood stagnation, and *qi* depression. Therefore, with these distinct but overlapping etiologies, each has different treatment guidelines, even though some treatments are similar.

Despite the tremendous recent progress that TCM has been made in exploring some effective treatments for dementia, critics exist. One critique is that researchers and authorities of TCM employ the biomedical mode of thinking and methods to study TCM, such that TCM is gradually losing its "traditional" characteristics, while biomedicine is becoming the "gold standard" to evaluate TCM (Jia 2005). Therefore, even though substantial efforts have been made to objectify the knowledge of TCM according to perceived universal standards, TCM has made relatively little theoretical progress and its application is actually increasingly shrinking in the medical community. This is evidenced by clinical practices of dementia care. Unlike Chinese neurologists who have been actively involved in promoting dementia care, TCM physicians have taken a rather conservative attitude towards dementia. For instance, there is no specific memory clinic for dementia patients in tertiary hospitals focusing on traditional Chinese medicine and acupuncture in Shanghai. Although there are hundreds of TCM practitioners in Shanghai, only a few are well-known experts in dementia care. Even so, in diagnosing dementia, they primarily rely upon TCM standards.[19] Moreover, TCM practitioners, like neurologists and psychiatrists, have failed to offer a euphonic term to name this illness condition. Rather, they continue to use the derogatory *chidai* to name dementia. For example, in one of the latest TCM training textbooks, *Science of Acupuncture Therapy* (Du and Dong 2016), *chidai* was the term used. Prescriptions for patients with dementia visiting TCM doctors are herbal medicines, and each patient is treated differently according to their underlying causes. Though TCM has been modernized in many ways by the state (Andrews 2014; Scheid 2002; Taylor 2005), in an era that emphasizes efficiency and productivity, the public often criticizes TCM as old fashioned and ineffective. Therefore, only limited numbers of patients turn toward TCM for dementia care.

The continuing debate about representative authority in dementia care

The participation of different professionals with a variety of backgrounds in providing dementia care has expanded the scope of dementia conditions. Neurological concepts such as MCI, pre-MCI, and VCIND have been used not only in dementia studies, but also in clinical settings as a way of diagnosing dementia. This has been especially true since the Chinese-made Oxiracetam was approved by the Chinese Food and Drug Administration in 1997 (Zhao et al. 1997). Recently, the book *Contemporary Dementia Medicine* (2008) was published. In this book, Dr. Ma Yongxing and Dr. Yu Zhuowei, two well-known gerontologists in Shanghai Huadong Hospital, together with several prestigious neurologists and psychiatrists, introduced the concept of aging associated

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[19] Sometimes, some TCM physicians refer biomedical standards.

memory impairment (AAMI) to China. This concept was firstly proposed by Crook and colleagues (1986, 1990), referring to a normal decline of memory due to aging. By introducing the diagnosis and assessment of this concept, gerontologists have pushed forward the boundary between normal aging and dementia. Psychiatrists also actively contribute this transformation by introducing new concepts such as mild behavioral impairment (MBI) into dementia studies. MBI was first proposed by the Alzheimer's Association International Conference 2016 in Toronto,[20] and was quickly introduced to China and Shanghai Mental Health Care Center in a national research program. The argument for introducing MBI is that before the memory decline of Alzheimer's disease, symptoms such as anxiety, agitation, social appropriateness and disorientation are common and troubling to family members. Thus, MBI aims to identify a new clinical stage in Alzheimer's disease which not only focuses on memory but also encompasses behaviors. Although this argument sounds scientific in providing the efficient and accurate diagnosis, its potential side effects, such as pressure on the society, community, family and individuals, are beyond imagination and control. Compared to biomedical concepts, TCM plays a secondary role in medicalizing dementia conditions. This is primarily due to the lack of a validating social structure for TCM, such as laboratory examinations, the biomedical instruments, etc. However, unlike the Mao-era China when TCM played a passive role in transforming itself, in contemporary China, TCM practitioners have to actively transform themselves by equipping themselves with biomedical knowledge so that they can communicate with biomedical professionals. By engaging the exploration of effective treatment for dementia through both biomedical and

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[20] https://www.alz.org/aaic/releases_2016/sun_445_ET.asp, accessed May 3rd, 2018.

TCM methods, TCM practitioners establish their professional status in the medical community. Even though they are playing a minor role currently in dementia care, their status will change as long as more state and personal efforts devote to the further development of TCM.

Discussion and conclusion

This chapter has outlined changing conceptualizations of dementia through the historical examination of interactions between Chinese states officials and medical professionals as well as the interrelationships between biomedical and ethnomedical professionals. Medicalizing dementia as a stigmatized mental disorder is embedded in the social and historical contexts of a devalued person in Chinese culture. Such biopower is organized through state ideologies in governing human bodies as well as formulated by medical professionals in producing "scientific" knowledge. By conjoining biopolitical strategies during the process of medicalizing dementia, the power of state and professionals transformed life into bare life (Agamben 1998), and thus created a political space of neglect.

Building upon Muhle's (2014) argument that biopolitics itself *is* a form of life which oscillates between the natural dimension and social manipulation, this chapter has broadened the scope of what constitutes the *life* of biopolitics. Similar to other anthropologists' work in framing biopolitical analysis (Cohen 1998; Kitanaka 2012; Mahmood 2005; Traphagan 2000; Zigon 2011), this project has revealed how state and professional powers play a central role in establishing social norms, which shape basic understandings of dementia. However, this centrality is dynamic because different state ideologies have laid different foundations through which Chinese medical practitioners can perform their authority. In practice, Chinese professionals have participated in approaching but rarely played a dominant role in creating official norms or standards for diagnosing dementia. Moreover, the shifting of state ideologies – manifested by the transition from nationalism to communism, and from communism to capitalism– have created discrepancies in what kinds of scientific knowledge has actually been employed. As shown in previous sections, these discrepancies result from a configuration of knowledge-power relations. It is the intra-dynamics of state-professional power that shapes the specific *life* form of biopolitics itself.

This study makes the *life* form of biopolitics in China explicit through examining the governing strategies of dementia, i.e., how states wielded power to influence healthcare practitioners in conceptualizing dementia. Unschuld (2010) argues that "the acceptance or rejection of concepts of disease by groups in society has rarely been independent of socioeconomic and sociopolitical determinants, be they consciously considered or not" (11). Changes in the conceptualization of dementia by different healthcare practitioners in China were closely related to historically-contingent social economic and political conditions. In imperial China, the theoretical format of TCM as well as its application functioned within a social structure that validated its values. The social structure of imperial China was characterized by Confucianism and Taoism, emphasizing order and harmony. Dementia as madness challenged these social norms, therefore, it was considered as a stigmatized illness. In understanding dementia, TCM viewed it from a holistic perspective – integrating physiological function with psychological functions of the body – which was fostered by Taoism. Dementia was an unbalance of the integrated biopsychological system, which might be caused by cosmological and/or natural forces, such as ones' ancestors or punishment from the gods. Therefore, the threat to one's social values of order and face was even more tremendous than the disease itself, which was evidenced by inhuman confinement of dementia patients by either their families or local governments (Lin 1981; Ma 2014).

The social unworthiness of a person with dementia has continued from prerevolutionary time right up to contemporary days in China; however, the strategies each regime employed have been different. In Republican China, the state turned to biomedicine for governing dementia and TCM was severe attacked during this period. This was not only because TCM beliefs often created cultural barriers to the practice of Western-style psychiatry in China, but more importantly, through establishing a modern health care system, the nationalist government could build a nation based on science that computed with Western sense. In addition, the necessity of controlling social deviants required political reform to build a modern nation through medicalization of the mind. The conceptualization of dementia as biosocial deviance by the nationalist government and medical authorities was based on Japanese and American models. However, in Maoist China, these models were viewed as "bourgeois"; psychiatrists who adopted these models were required to undergo political re-education to follow the Soviet paradigm. Correspondingly, dementia was considered to be a "product of capitalism," which required not only medical therapy, but also ideological re-education and labor therapy to equip patients with communist thoughts. In order to serve the interests of the political cause, the state had to build a healthcare system to assist the revolution, which integrated TCM as a potential force for nationalism. In such a political context, TCM was transformed into a medicine of social revolution (Taylor 2005), even though its status remained peripheral in mental healthcare.

Governing strategies of dementia evolve along with the deepening of governmentality in China. In the reform era, dementia has been understood from a biological perspective by professionals such as psychiatrists, neurologists, TCM practitioners, and gerontologists. During the Mao-era and the early stage of the reform era (1978-2001), the state selectively adopted biomedical concepts and was actively involved in establishing the Chinese classification of mental disorders. However, the recent, massive biomedicalization of human conditions associated with dementia is dominated by a new generation of Chinese healthcare professionals who prefer to communicate with the international community. Ostensibly, these professionals had finally established their global authority by medicalizing human conditions and behaviors associated with aging. However, this form of "power" was naturalized within the global context of mental health and population aging as well as the neoliberal emphasis on self-care and individual responsibility (Crawford 2006; Kaufman and Fjord 2011; Muhle 2014). Meanwhile, medical knowledge is standardized for the purpose of science, especially in the field of psychiatry and neurology, resulting in a clear division between "normal" and "abnormal." While acknowledging the benefits of standardizing medical knowledge to international communication, research, and administration, we should be consciously aware that adopting biomedical concepts without a critical attitude and an awareness of cultural barriers becomes another type of governmentality. This new type of governmentality is highly associated with the rise of the modern state which tends to improve health conditions of the population through medical and pharmaceutical companies (Conrad 2007), which shifts the responsibility from the state to an individual in healthcare.

In the following chapters, I will explore various cultural effects of such biopolitical governance, namely moral consequences of stigmatizing dementia, connections between each patient's life and family and their surrounding social environment, as well as the unfolding of aging policies and social services in Shanghai.

Chapter 2 Negotiating a Sociopolitical Space for Elders with Dementia in Shanghai

Introduction

Dementia care poses serious challenges for long-term care systems in many societies. China deserves special attention because it has the largest number of dementia sufferers in the world. According to estimation by ADI (2015), there were more than 10 million dementia sufferers in China. Medicalization, which unfortunately has reinforced the stigma surrounding dementia in China (Ramsay 2013; Zhang 2018c), transforms the care pattern for this group of people. Previously, dementia conditions were considered as signs of normal aging, and seniors with dementia symptoms were cared by their family members without social stigma (Ikels 1998). Since the medicalization, people living with dementia mainly receive care from medical institutions. The day-to-day work of dementia care is a family obligation and inappropriate to discuss in public settings. In order to avoid stigma, domestic settings become the primary sphere for dementia sufferers. As a result, social services such as nursing homes and community-based programs supporting people with dementia and their families remain underdeveloped in China. Within the existing eldercare industry, most nursing homes are reluctant to enroll people living with dementia because of the liability.

However, the increasing number of elders with dementia in China has transformed this issue from a private problem to a public concern. Nationwide dementia-friendly campaigns initiated by various stakeholders are changing the landscape of dementia care. Among these stakeholders are eldercare service providers, directors of local nongovernmental organizations (NGOs), medical professionals, public media producers, for-profit corporations, family caregivers, and some government officials. A synergistic approach, which aligns state and non-state actors, has been formed to deal with the challenge of dementia care. In Shanghai, some institutional and individual agencies facilitate governmental actions to deal with the potential threat of dementia. In response, the Shanghai government has proposed building dementia-friendly communities by 2030. Embedded within this project were policies that allocated social resources to institutions engaged in better dementia care. For instance, in 2018, the Shanghai government initiated the project of building dementia-care units within nursing homes and community-based eldercare facilities. In practice, services around dementia care followed global models for dementia care (e.g., social inclusiveness and person-centered care) introduced by local NGOs. The emergence of the notion of dementia-friendly communities, and the acceptance of global humanitarian care ethics, signals a strategic change in dealing with dementia in China.

Not everyone in Shanghai would embrace these Western beliefs and practices, particularly when the activities of advocates for better dementia care challenge the community power structure. For example, the project of building dementia-friendly communities mandated that each community built dementia-care units. Their locations in certain neighborhoods, however, have challenged the power structure within these communities. Traditional cultural values, such as social order, family responsibility, and personhood based on cognitive ability, remain popular among the public. A significant aspect of maintaining social order is *fengshui*, which refers to the configuration of land forms, bodies of water, and the built environment that direct the flow of universal *qi*.

Correct *fengshui* can improve a person or a family's wealth, happiness, and longevity and vice versa (Bruun 1996). In building houses or other infrastructures in neighborhoods, people seek to maximize their own gains through manipulating the flow of natural *qi*, without regard for their neighbors. Building dementia-care units in Shanghai neighborhoods, to some extent, damages the *fengshui* fortunes of nearby residents. As a result, several of these dementia-care units encountered resistance from local residents. During my fieldwork in 2017, I witnessed these tensions between advocates and residents.

This chapter explores the localization of global humanitarian care ethics for dementia sufferers and resistance against these care ethics and practices. First, I analyze the social transformation of attitudes toward elders with dementia, which is being promoted by state and non-state advocates. To better understand their work, I examine the motivations of state and non-state advocates who promote better dementia care. After that, I discuss the local resistance to the project of building dementia-care units in neighborhoods. I argue that advocates and detractors of dementia-care units correspond to global forces and local transformations of Western thoughts. Seen in this context, the attempts of and resistance to building dementia-friendly communities in Shanghai have created a powerful site between global and local forces, modern and traditional values, and individual and collective benefits. By analyzing these tensions, this chapter also reveals the workings of community-culture power, which that might undermine the promotion of dementia-friendly projects.

Motivations of Advocates

This section discusses the advocates who started the project of building dementia-friendly communities in Shanghai. Although dementia care programs remain spotty, each advocate’s actions suggest that the rising community dementia care projects in Shanghai are not only creating a social space for the exercise of civil and political equality, but also assisting a distinct ethics of dementia care. Therefore, it is crucial to examine the motivations of those who initiated these programs to understand why dementia matters to them and how dementia care is envisioned by advocates in reform-era China.

People engaged in building dementia-friendly communities in Shanghai include local NGO campaigners, nursing home managers, government officials, intellectual elites, and social media producers. They range in age from early 20s to 50s. All of them received high education, and some were trained, worked or travelled overseas. Before shifting their attention to dementia care, they accumulated various knowledge and skills, including nursing, business management, computer science, social work, and/or public health advocacy. Some were government officials or medical professionals. All of them came equipped with a vision for better dementia care.

Among the various people engaged in the moment for better dementia care, some have had personal experience with poor dementia care in China, and later turned their personal misery into social action. For example, Mrs. Gu, after witnessing how hard it was for her mother to take care of her grandma with dementia, established an NGO supporting family caregivers of elders with dementia in Shanghai. Similarly, about ten years ago, Dr. Bao, who used to be a clinical doctor in a hospital, decided to build a nursing home for elders with dementia. He did so because his grandma was diagnosed with dementia, and there were no nursing homes enrolling dementia sufferers in Shanghai unless you had special tie with a nursing home manager. Likewise, Mr. Tang who used to be a manager of a tour agency established a local NGO with the support of the community government. He also witnessed his grandma suffering from dementia and poor care. His NGO specialized in promoting public awareness and non-pharmaceutical interventions into dementia.

Government officials who had personal ties with dementia sufferers have also attempted to achieve better care for these people. In a community of the Jing'an District in Shanghai, there was a government-sponsored senior center specializing in dementia intervention. This organization received special attention and support from Mr. Fang, who was a governmental official in charge of civil affairs for the district. His mother died of dementia about eight years ago. As a result, Mr. Fang visited several urban nursing homes in China and noticed that there were very limited dementia care facilities, in spite of the increasing number of elders with dementia. He went to Taiwan, Hong Kong, Japan, and Australia to learn how people around the world deal with dementia. Meanwhile, he consulted local psychiatrists about intervention strategies for elders with dementia. With various avenues of support, Mr. Fang finally established the dementia-care unit in Jiangan in 2012. Similarly, another government official at the municipal level, Mr. Chen, actively advocated on behalf of dementia sufferers and their family caregivers. He witnessed his uncle suffering from dementia and his families' distress due to caregiving. When he learned that dementia might be inherited, he worried a lot about his father and the millions of other family caregivers. Eventually, he endeavored to direct the policy for building dementia-friendly communities in Shanghai. With his appeals to upper-level government officials, existing policies around this project were augmented, including the establishment of dementia-care units in eldercare facilities.

Several intellectual elites who participated in promoting better care for elders with dementia are worthy of special attention. These people engage in training or providing support to NGOs and nursing homes. Like the aforementioned individuals, these intellectuals have similar personal experiences with dementia. For instance, Mrs. Hong, who majored in public media, had about fifteen years of work experience in advertisement. In 2007, after her grandmother died of dementia, she devoted herself to better dementia care in China. In order to introduce professional dementia care modes, she worked with Alzheimer's Disease International (ADI) in Britain and Australia. In 2011, Mrs. Hong and Dr. Wang Huali, who was a psychiatrist at Beijing Medical School, published the book *Smart Family Caregivers of Elders with Dementia,* which was the first book to systematically introduce and explain how to deal with daily behavioral and psychiatric problems for family caregivers in China. Moreover, she and her team introduced the project, Dementia Friends, into China. This project focused on the education of community dwellers. They also facilitated the process of turning their understanding into action to support elders with dementia and their families. In 2016, she and her colleagues started the first national training program for nursing home managers, staff and family caregivers. This program was mainly about person-centered care skills and practices in the Chinese context. When I conducted my fieldwork in 2017, I attended their second annual training program in Shanghai. In the opening remarks of the training program, Mrs. Hong expressed her regret about the poor family care for her grandma, saying, "If we could do it again, I believe we would do much better than before."

Like Mrs. Hong, Dr. Liu is another public figure engaged in dementia care. Dr. Liu is a professor at Shanghai Normal University in Shanghai, but received his Ph.D. in social work in Japan. Before he received his degree, his grandmother died due to dementia. He felt regretful and guilty about his failure to perform the duties of filial piety. After that, he engaged in promoting quality care for elders with dementia by collaborating with local NGOs and nursing homes. Because of his frequent visits to Japan, he was able to introduce many advanced forms of dementia care to Shanghai, such as culture-based dementia care. He also actively promoted this Japanese dementia care model with local NGOs by emphasizing the role of social workers in linking elderly clients' needs to social support. His personal endeavors have facilitated the development of professional care for elders with dementia in China.

In addition to the above individuals who had families with dementia, some social elites without such personal experiences have also worked to improve dementia care in Shanghai. Some are private nursing home managers, and others collaborate with local government to operate community-based mini-nursing homes or senior centers. They have extensive social networks that include local intellectuals and international dementia care experts. For example, Mr. Xu, a former business manager who started institutional eldercare in 2013, ran a private nursing home and a senior center specializing in dementia care. He worked closely with local neurologists, gerontologists, psychiatrists, and a dementia care expert from Denmark. Mrs. Wang, also a former business manager, has been engaged in better eldercare practices since 2013. She worked closely with different levels of the Shanghai government and eldercare experts from California. She also actively introduced these foreign experts to Chinese eldercare experts by hosting small-scale meetings of the Sino-American Eldercare Forum. With the direction of these foreigners and local government support, she started dementia care at a nursing home and a community-based mini nursing home in 2015. In our conversations, Mrs. Wang expressed her goal to promote better eldercare for Chinese seniors: “We are trying to build an institution that we would like to stay in our old age.” In addition to these business managers, I interviewed two nurses engaged in promoting better dementia care. These two nurses has been improving their dementia care skills since 2012. They undertook private nursing home management because of the poor services in public or hybrid private-public eldercare facilities. After their years of working in nursing homes, they gradually realized that dementia was a challenge for traditional eldercare facilities. Because most public or hybrid nursing homes did not enroll elders with dementia, private nursing homes took risks to enroll these elders. For all these nursing home managers mentioned above, the primary motivation was to improve the quality of dementia care in China. One nursing home director criticized the negative public attitudes toward dementia sufferers: “China will not be able to enter into the ranks of modern nations if we continue to treat them [dementia sufferers] as nonpersons. We should change the negative aspects of our traditional culture.”

In addition to the personal devotion to improving dementia care, some intellectual elites take advantage of public media to increase public awareness. For instance, in 2017, the first documentary film on this topic, *Please Remember Me (wo zhi renshi ni),* premiered in Shanghai. This movie documented the daily life of a ninety-year old couple, with the wife suffering from dementia in Shanghai. Director Zhao Qing and her assistant were nieces of this old couple. This film presented the dilemmas of living with dementia patients, such as how to deal with the decline of cognitive abilities. In addition, this movie documented the conjugal love between the old couple and the dignity the patient valued late in life. Since it was released, this movie had been shown for free in communities, colleges, and related pharmaceutical companies across Shanghai over 100 times. This movie raised a public discussion about the kind of support that could be provided for this group of people.

The above analysis has shown people engaged in dementia-friendly campaigns come from various social spheres. Although each advocate works independently, I argue that their activities together create a sociopolitical space for dementia sufferers, in which both advocates and dementia sufferers can exercise their civil rights. Advocates felt a moral imperative to improve dementia care in China, and moral reasoning is especially strong for those who had family members with dementia. They devoted time and energy to this social cause and some even changed their career paths. They engaged in this social cause not because it could result in a personal success or bring personal economic benefits. Instead, they felt a deeply moral debt to their family members with dementia, and some even believed their actions could enable China to enter into the ranks of modern nation. This moral obligation drove people to engage in better dementia care. No matter what they were doing, they wanted the voices of dementia sufferers and their families to be heard. By engaging in different activities, they showed the support for numerous families and dementia sufferers. This process also facilitated their moral elevation since they all prioritized social meaning over the economic value of their work.

Practices of Advocates

Equally worth mentioning is the increasing number of activities held by institutions to deal with the urgency of dementia care. These institutions include research centers, the eldercare industry, pharmaceutical companies, and local NGOs. In the academic community, the Shanghai Health Development Research Center and the Shanghai Medicine and Health Development Foundation, which are affiliated with the Municipal Bureau of Public Health, held an international conference to promote the prevention of and intervention into dementia in 2017. In addition, the Shanghai Science and Technology Center financially supported a three-year project to facilitate diagnosis of mild cognitive impairment (MCI) in multiple research centers. This project aimed to identify 5,000-10,000 MCI patients in five tertiary hospitals, fifteen secondary hospitals, and forty community-based hospitals, and to frame out a referral model for MCI patients. Meanwhile, the Alzheimer's Disease Diagnosis and Treatment Center, which is affiliated with Shanghai Jiaotong University, received two research grants on MCI intervention. Similarly, pharmaceutical companies and eldercare companies also held both national and local meetings to discuss the challenges of dementia. The nationwide "9·21" event (i.e., International Alzheimer's Day) was financially supported by Eisai China Inc.[21] The Toyota Consortium also financially supported the exchange of dementia care experts in Shanghai and Japan through meetings, travel, and on-site visit. The Nichii Eldercare Company was one of the famous Japanese eldercare companies in China that specialized in dementia care. Local eldercare companies and NGOs also held nationwide meetings in Shanghai (e.g., the Lujiazui Summit Meeting on Eldercare) to facilitate the professionalization of dementia care. Local NGOs such as Jian'ai Charity, Jinmei, Ailaojiayuan, and Xintu, which specialized in dementia care and family support, also engaged in the public awareness of dementia. Although effects of these NGO activities were limited in scale, each NGO had been working closely with local government and

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[21] Eisai China Inc. is a Japanese pharmaceutical company, and Aricept is a cognitive-enhancing medicine of this company. So far, China is the largest market for this drug.

community dwellers. Together with the aforementioned individual advocates, these social activities have been transforming the landscape of dementia care in Shanghai.

Although conventional care models still dominate the eldercare industry, the recently imported Western humanitarian forms of dementia care provide guidelines for professionalizing eldercare services. During my fieldwork, person-centered care has been constantly mentioned by various stakeholders. Each stakeholder acknowledged its importance and tried to put this concept into practice. In eldercare facilities, person-centered care has been divided into three approaches throughout the progression of dementia. In the early stage, person-centered care treats each individual as an independent person who needs occasional assistance. The three senior centers I visited usually organized group activities for elders with early stage dementia, including baking, paper-cutting, singing, finger-exercises, Tai Chi, etc. Elders without dementia also joined these activities as preventive strategies. Unlike conventional care, which often focuses on services, person-centered care pays attention to the interactions between service providers and care receivers. No matter how simple these activities seem, when put into practice, all of them require emotional commitment and genuine care, particularly when seniors are experiencing loneliness. A service provider from a senior center expressed the importance of these values embedded in dementia services:

> These elders are not like those who have completely lost cognitive abilities. They are able to do a lot of things but are extremely lonely at home because they do not live with their children. In addition to providing services, we try to make them laugh and talk to them. If they do not feel your genuine care, all services

> are useless. When they feel your love and care, they will be very grateful. (PTW20170918)

Person-centered care has been contextualized to include psychological services in Shanghai. Those with mild cognitive impairment might be considered as “patients” from the biological perspective. However, from the perspective of service providers and designers, these elders are suffering from social deprivation of love and care, rather than a disease. Person-centered care, with a universal emphasis on personal care, varies from context to context in practice. In China, where rapid modernization is occurring, person-centered care is contextualized as a service to make seniors—especially those with mild cognitive impairment—feel cared for, connected, and supported.

In the middle stage, elders with dementia gradually lose their physical and cognitive abilities. Unlike conventional eldercare, which aims to fill in for their lost functions (difficult-based), person-centered care pays attention to the remaining functions (strength-based) and argues that each individual can maintain or recover certain abilities through appropriate training and exercise. The rehabilitation programs for elders with dementia in most (mini) nursing homes I visited served this purpose. Moreover, in dealing with behavioral and psychiatric symptoms, traditional eldercare usually turns to biomedical treatment. However, person-centered care believes that dementia symptoms can be relieved through non-pharmaceutical strategies, and drugs should only be used when nurses and staff have no other options. Yet, these non-pharmaceutical interventions require a lot of emotional commitment. A dementia care program director in a nursing home briefly introduced their prioritization of non-pharmaceutical interventions:

> … These activities are equal to sensory stimulation. We also have occupational therapy, memory training, and if some elders can cooperate, we will ask them to memorize Tang Dynasty poems and recall their past, to wake up their long-term memory. Even though we have done so much, there are still cases we cannot handle. For these elders, we will try to figure out the best way to fit the person. When there are psychiatric symptoms and violent behaviors, we will try to understand his/her conditions and figure out the underlying causes. If this method does not work, we will try another one. So, it requires our nursing aids to be very patient. (HYT201706)

Valuing the remaining function of dementia sufferers characterizes the person-centered approach in institutions. Activities are especially designed to maintain their physical and cognitive functions. When aggressive behaviors are manifested, non-pharmaceutical strategies are tried first, and biomedical treatment with drugs is the last choice. The emphasis on non-pharmaceutical strategies requires caregivers to devote a lot of time and energy to their practice. All of these efforts seem against the economic-centered social environment, which, to some extent, does not value the vulnerability of human beings. Dementia serves as a reminder of this universal aspect of the human condition, all being vulnerable, one degree or another. Correspondingly, person-centered care reminds us of the mutual dependence of being human in an institution and/or a society.

In conventional dementia care models, the lives of elders with late stage dementia are treated as unworthy of respect, and institutional care for such elders mainly focuses on basic life support and pharmaceutical restrictions. However, person-centered care pays close attention to clients' remaining abilities (e.g., communication) and the need for dignity and respect even in the late stage of dementia. This entails intensive emotional devotion from nursing aids and other staff. When I visited person-centered nursing homes, their high standards for dementia care were translated into routinized daily practices, e.g., feeding food, fluid intake, personal hygiene, protecting from bed sores, bathing and dressing, etc. On the surface, these practices seemed to be no different from basic life support for elders without dementia. However, a nursing home director underpinned the embedded ethics in the routinized care practices:

> Dementia care is burdensome, because your client becomes weaker and weaker at late life stage. Their conditions can only become worse without any possibility of becoming better. This is the tendency. Why do we continue to do this? We are doing this because we hope when we become old, someone can treat us like we treat these elders. Eldercare is easy to do with these superficial infrastructures, but it is also a compassionate project, especially for taking care of elders with dementia at an advanced age. It needs our emotional devotion. (HDC201711)

Specifically, in other words, actions must be done with devotion, not just done medicinally. Also, those compassionate facilities were against the tendency to over-medicate patients. Professional care for elders with late stage dementia distinguishes itself from conventional care by incorporating Western humanitarian care ethics, such as social inclusiveness and emotional commitment. These practices are valuable in contemporary Chinese society, considering rapid modernization and the entrenched social stigma associated with dementia. Through person-centered care, service providers can give their care recipients with dementia some semblance of dignity, which in turn makes their care work feel noble and unsullied. Currently, practices of compassionate care for dementia sufferers remain inadequate in China; yet, these pilot models provide a way to think about principles that can guide compassionate dementia care and a possibly transform of the culture of dementia care in Shanghai.

Protests and the Accountability of Culture in Developing Dementia-Friendly Services

These aforementioned advocates and their practices aim to transform the way we evaluate personal relations, professional status, and public policies regarding dementia care. When I asked about their struggles and challenges, most pointed to a cultural environment that was negative toward dementia sufferers. In Chapters 1, 3, and 6, I discussed the entrenched stigma that was rooted in traditional Chinese culture. Here I focus on another cultural element—*fengshui*—to discuss the role of physical environment in developing or facilitating to develop culturally appropriate services for dementia sufferers.

The rationale of building community-based facilities is to enable seniors to age in place and to reduce expenditure on institutional care. These facilities play a vital role in the eldercare system due to their accessibility and affordability for most elders in urban China (Chen and Han 2016). Their specific locations in a community, however, can cause conflict with local residents. In Shanghai, these conflicts became intense when local government initiated the community-based mini nursing homes in 2015. A project director, who was an architectural designer in a famous eldercare enterprise, conducted a survey in several cities in China. He found that almost two thirds of community-based eldercare facilities in urban China encountered resistance from local residents during the period of construction in 2015 and 2016, and more than one third of these facilities were suspended or cancelled due to the local resistance (Zhang 2018a). According to this director, factors leading to the failure of community-based eldercare facilities included the poor infrastructure system, the isolation of these facilities from the community, and improper community administration. In addition to these structural factors, my ethnographic data reveals that cultural understanding, such as the fear of *fengshui* damage by eldercare facilities, is another cause of the local resistance.

Fengshui, literally wind-and-water, refers to the configuration of land forms, bodies of water, and the built environment in directing the flow of the universal *qi*. During my fieldwork and my previous work experience, I was constantly told by *fengshui*-believers that the city of Shanghai was a positive example of successfully manipulating natural *qi*, namely the East China Sea and the Yangtze River. The name "Shanghai" means "into the sea" and "above the sea," indicating its affinity with water. Coincidence or not, Shanghai and its surrounding cities are the most prosperous area in China. Within the city, *fengshui*-believers try their best to generate fortune by manipulating natural *qi*, which mainly generates from the Huangpu River and the Suzhou River, two famous rivers that flow through the city. *Qi* is not limited to rivers; rather it exists in everything that has contacts with life. Correct *fengshui* can improve a person or a family's wealth, happiness, and longevity and vice versa (Bruun 1996). In building houses or other infrastructures in neighborhoods, one will seek to maximize his or her own gains through manipulating the flow of natural *qi,* without regard for their neighbors. Some residents shared with me how fengshuists had changed their years of bad fortune after changing their housing location, inter design, or even furniture.

The social competitiveness intrinsic to *fengshui* arises among neighborhood residents over the placement of community-based eldercare facilities, especially when the position of these facilities does not favor nearby homeowners. While acknowledging that eldercare is a booming industry in China, eldercare facilities are still relatively new social institutions. Traditionally, only those most miserable and lowest status people such as those "without relatives," "without income," and "without living place" would stay in nursing homes (Kaufman et al. 2013). The Chinese geomancy further colors eldercare facilities. In *fengshui* cosmology, elderly people—particularly those with chronic illnesses—are considered to have severe *yin*[22] and are not healthy to be around. Correspondingly, nursing homes—which constantly deal with death and dying of elders—are treated as places with severe *yin.* According to geomantic ideology, these places consume the *yang*[23] energy and minimize the fortune of individuals nearby.

Community-based eldercare facilities, namely the mini nursing homes with overnight functions and long-term residents, particularly challenge the geomantic traditions. When individuals confront bothersome difficulties that modern science cannot explain well—such as mental disorders, accidents, and business failures—they will turn to *fengshui* specialists to examine their surrounding environment (Bruun 1996; Mahoney et al. 2005). Community-based eldercare facilities were blamed for draining the optimal *qi*, because they gathered too many elders and sick people together. Some residents told me that they could "see" and "feel" the negative *qi* of senior centers, because "it [this place] touches me." Therefore, severe resistance from local residents in urban China arise frequently

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[22] Yin in geomancy refers to negative, dark, and feminine energy, which is often associated with bad fortune.
[23] Yang refers to positive, bright, and masculine energy, which is often associated with good fortune.

(Chen et al. 2016; Liu 2016; Shao and Li 2015). In some extreme cases, local residents put up a banner with a slogan "Get out, Senior Centers" to resist the construction work (Chen and Ren 2016; Li and Gong 2016). Being filial to one's own elders did not extend to other people's aging family members in this case. Among the six communities with mini-nursing home projects I visited during my fieldwork, two met with severe resistance from residents. The failed project in B community, to some extent, was believed to bring a damaging effect to the residents' health and wealth. The intended location of the senior center was located almost in the center of the neighborhood. According to the director of the Residents' Committee, it was a public playground for residents, and most often, kids. From the *fengshui* perspective, this public space, which gathered the most vibrant people, brought fortune to all the residents around. If it was replaced by a senior center, it would gather the most vulnerable people, and accordingly this senior center would consume the fortune of nearby residents. A resident expressed her point of view about the relationship between eldercare facilities and neighborhoods:

> Each household has elders now, and we are also getting old. We all know that these eldercare services are good. That does not mean you can put all those dying persons together in one place in our neighborhood. You go out and see people alive, and they are normal. Suddenly, there is an eldercare facility, and the ambulance comes back and forth every day, sometimes with dead people. Then you will feel uncomfortable in this neighborhood. You feel your energy drained. (HWYZhou201710)

The dementia-care project in C community also encountered similar resistance from local residents; however, the local government and the third party administrator (i.e., the mini-nursing home company) compensated nearby residents, resulting in a temporary harmony. A program director in C community told me as following:

> This mini nursing home was almost a "miscarriage" [cancelled]. The government and local Residents' Committee as well as the third party [the mini-nursing home company] all showed up to do the "thought work" with nearby residents. The government told the nearby residents that they would be given preference if they wanted family members to enroll in the facility. Meanwhile, the construction work disturbed the residents, so the third party [the mini-nursing home company] had to compensate them. It's like 'mouth-sealing fees.' I don't know how much these residents get from the government and the third party, but I am sure they have to have these "small actions" [under-the-table agreement], otherwise the project would fail. If they don't give these gifts, the nearby residents will go wild again when the opening ceremony starts tomorrow. (HWYCai 201708)

This harmonious relationship could end whenever residents stop tolerating disturbances by eldercare facilities. When the director of the mini-nursing home in C community invited me to give a presentation about dementia, I witnessed a verbal conflict between nearby residents and the director of the nursing home.

> Resident A: "Why are you so noisy? Can't you close your door? If not, I will call the municipal office!"
>
> Resident B: "What are you doing here? How can you be so loud?"
>
> Resident C: "You are killing us, you brain-damaged people!"
>
> Resident D: "What's wrong with you?! So loud!"

Director: “You are loud and noisy every day; you even play mahjong at midnight! You greedy people only yell when we have guests here!”

These conflicts were caused, according to several residents’ points of view, by the *fengshui* disturbance of senior centers. Because of the negative association of seniors based on *fengshui* belief, most nursing homes in urban Shanghai are located on the outskirts or areas that are far away from neighborhoods. For example, among the nine nursing homes I visited, seven nursing homes were located very far away from neighborhoods. Only two nursing homes were located in neighborhoods, and they also encountered resistance from local residents. Eventually, they had to change the door from the neighborhood side to the highway side, so that nursing homes’ *yin* did not affect nearby residents. From the *fengshui* perspective, the door—through which people come in and go out—brings both positive and negative *qi* to a family, an institution, and a community. Since nursing homes have accumulated so many elders who are emitting yin and sucking up *yang* energy, it’s better to place these institutions outside of town or change their doors into a position that will minimize the negative impact.

Ignoring local beliefs and cultural practices can undermine the efforts to advocate for dementia-friendly communities in Shanghai. Although Chinese culture regarding eldercare has undergone dramatic transformation, community-based eldercare facilities remain foreign, and attitudes toward death and dying remain wary stereotyped. A nursing home manager, who has been working in an eldercare facility in Shanghai for more than twenty years, expressed that most families did not expect their elderly kin to die at home. Some families would send these elders to die in a hospital if their financial situations allowed them to do so; yet, other families would send the dying elders to nursing homes so that they could save both money and effort. Yet, when nursing homes enrolled dying elders or elders with chronic illnesses, local residents would jointly attack the nursing home directors (Lin 2014). These paradoxical aspect of contemporary Chinese culture, namely showing filial piety to seniors on the one hand and stereotyping elders with chronic illness on the other, demonstrate how both individual and collective benefits should be taken into consideration in order to develop culturally appropriate services. Dementia conditions are especially challenging because these symptoms threaten the order of social environment.

Social environment serves as an important index to evaluate whether a service is culturally appropriate for clients, community, and other stakeholders. The Chinese *fengshui* belief addresses the importance of understanding cultural and community context when dementia-friendly services encounter local resistance. The transformation of Chinese society from a traditional one to a modern one does not mean that traditional elements are irrelevant in people's daily life. Citizens constantly refer to traditional values for guidance of their behaviors, particularly when modern thoughts fail to deliver individual and community benefits. We have observed the multiple streams of culture in a so called "modern" city, Shanghai. Realizing the importance of culture for developing dementia-friendly services, we need to know how to respond to these conflicts—seeking a common ground among various stakeholders, rather than set a clear boundary between different social groups. Culturally competent services regain a critical consideration of balancing benefits between dementia sufferers and community members.

Discussion and Conclusion

This chapter has discussed various stakeholders who advocate on behalf of dementia patients and their families, practices that embed person-centered care, and local resistance to the dementia-friendly projects in communities in Shanghai. While negotiating a sociopolitical space for elders with dementia has facilitated the transformation of public attitudes toward dementia, it also negatively affects some detractors, particularly regarding the potential harm to their *fengshui* fortune. Understanding both advocates and protesters also helps us grasp how the globally circulated discourses and practices of humanitarian ethics interact with local care paradigms to influence individual and collective life. Moreover, it helps us to reevaluate the role of physical and cultural environment in developing dementia-friendly services.

Cultural variables serve as an important context to understand the ways in which power is used and defended. Advocates and protesters surrounding community-based dementia care facilities demonstrate the contradiction between the Western humanitarian care ethics and traditional Chinese cultural norms, between the collective care burden and individual benefits, and between government's intention to provide dementia care and its limited ability to provide community-compatible services. Borrowing the Western concept of dementia-friendly communities, the Shanghai government mandates that communities address local dementia issues by both building dementia-care units to accommodate and provide services to dementia sufferers. However, initiatives that simply promote a Western concept are not fitting comfortably with local norms and expectations, as numerous anthropological studies have revealed (Feldman 2017; Ikeda and Roemer 2009; Singer et al. 2016). The ignorance of cultural beliefs about eldercare facilities transforms the nature of these projects from social care to social conflicts. The outcome is local resistance from residents. The cultural obstacles to dementia care complicate the role of state power and community and individual agency in China.

This chapter also demonstrates the realignment of state and non-state actors in building dementia-friendly communities in Shanghai. Internal and external forces, often working synergistically, push governmental policies and programs on dementia care forward. External factors, such as international communications and interactions around dementia care, play an important role in pushing the Shanghai government to pay greater attention to the quality of social eldercare. Domestic events, such as the rapidly aging population with an attendant increase in the number of elders with dementia and the nationwide dementia-friendly campaigns, are the major impetus for local government in Shanghai to push to social change. Domestic advocacy amongst the government officials and social activists also spurs the Shanghai government to develop innovative dementia care strategies. Overall, a major force mobilizing quality dementia care is China's own internal advocates. These advocates collectively seize the opportunity to make connections between state and society and to convince senior leaders of the need to respond to the increasing number of elders with dementia. The dementia-friendly projects challenge the sole legitimacy of the authority of local governments in dementia care, as they are being prodded by civil society advocates and pushed back against by local protestors.

These advocates also feel a moral responsibility to engage in dementia-friendly campaigns. During Mao-era China, the state created a moral imperative to serve the people or to sacrifice oneself for others (Zhang et al. 2010). In contemporary China, however, individuals advocating for elders with dementia and their families are not dependent on particular hierarchical structures. Rather, these people try to do what they consider right or good, and continue to debate the meaning of human benevolence. Thus, intentions and motivations involved in this social action are self-driven, altruistic or quasi-altruistic, which is valuable in a country in “moral crisis” (Kleinman et al. 2011; Yan 2012). In the face of the dementia epidemic, some middle-class individuals deploy their moral agency—their moral debt to their families—to challenge the power structures that resulted in poor dementia care in China. Therefore, engaging in dementia-friendly campaigns is not only reconstructing the moral discourse related to dementia, but also serving as a pathway for individuals to cultivate their moral selves. Conversely, in order to demonstrate their moral status, individuals must shoulder responsibility to protect the lives of elders with dementia and their families from further threats or low care quality. In these cases, morality drives these individuals to pursue better care.

Meanwhile, building dementia-friendly communities draws the support of the state, including governmental policies, social resources, and networks, which further testifies to the co-constructing state-society relationship. These programs support a group of people with dementia, whose lives are socially unworthy in traditional Chinese culture that values cognitive ability. Thus, endorsing global humanitarian ethics, such as person-centered care, is transforming the public understanding of dementia as a stigmatized mental illness. In order to maximize the campaigns’ social effects, non-state actors have to work with local governments to institutionalize this set of ethical codes. Institutionalization also requires physical space, which must be provided by the state to ensure the legal status of these institutions. The establishment of dementia-care units in senior centers and (mini) nursing homes, as well as other dementia research programs, performatively creates a sociopolitical space not only for the practice of a distinct set of care ethics, but also for the exercise of civil rights and political equality. Part of the task of these programs is to thematize dementia care according to the progression of the disease. Although services for people living with early, middle, or late dementia are different, all point to the value of dementia sufferers' remaining functions and the necessity of social inclusiveness. These programs have less to do with the effectiveness of practices than with the political efficacy of making a new social identity, and thereby creating a new "life world" for elders with dementia. Therefore, the project of building dementia-friendly communities is both an expression of what is morally good, and a means to realize social benevolence. The appeal to a common moral imperative is a testimony to the co-constructive relationship between state and society.

Overall, negotiating a sociopolitical space for elders with dementia involves two different forms of local agency, i.e., advocacy and resistance. Each stakeholder endorses individual actions to generate some kind of collective benefits, no matter whether he/she is an advocate or a detractor. Their collective agency surpasses the fine line between individual rights and collective benefits. Politically, collective agency is no longer associated with a single party such as the state, but involves multiple stakeholders. Therefore, collective agency entails realignment and resistance. The advocacy and resistance are not only a result of coalition, but also a consequence of moral mobilization and reorientation in a rapidly changing society. The cultural obstacles of dementia-friendly projects and the moral attachment of these programs necessitate a holistic approach. This makes it possible to analyze the relationships between culture and power that are often ignored on developing social services.

Chapter 3 Debating “Good” Care: The Challenges of Dementia Care in Shanghai

Introduction

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, when 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 2017c). All of these factors lead to new debates about what constitutes “good” care to address population aging in China.

The increasing number of elders with dementia intensifies the debate around “good” care. Unlike Western societies where medicalization de-stigmatizes dementia, medicalization reinforces the stigma in China (Ramsay 2013; Zhang 2018c). Services are organized in a way that people with dementia passively receive care mainly from medical institutions, which directly threatens their health identity. In order to avoid stigma, domestic settings become the primary sphere for dementia sufferers. Social services such as nursing homes and community-based programs supporting patients and their families are underdeveloped.

Dementia-friendly campaigns recently initiated by various stakeholders are changing the landscape of eldercare in China (see Chapter 2). 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 various stakeholders.

In this chapter, I introduce two constructions of “good” dementia care in Shanghai. The governmental construction of systematic care—which emphasizes affordability, accessibility, and efficiency—is administration-centered. Systematic care invests in infrastructure, professionalizes services, enforces top-down governmental projects, and, often, ignores local contexts. However, non-state actors conceptualize “good” care differently, focusing on relational dimensions of care. Care as a way of conceptualizing personal and social relations in Western societies has been theorized by Barnes (2012). Humanitarian care ethics for dementia sufferers is built upon this theoretical approach. In this study, 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 2008; Confucius 1971). From the relationship perspective, there are some overlaps with the concept proposed by Barnes (2012). The difference is that relational care—with an emphasis on *ren* in China—is more about a paradigm than simply relationships between caregivers and care recipients. Building upon the Confucian ethics and the Western humanitarian care ethics, this relational care values social inclusiveness, genuine respect and support for elders, and the family-like culture in institutions. In practice, the systematic care and relational care often coexist in eldercare facilities, which often creates conflicts and resistance.

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

Ethnographic works have 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. 2010). 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 2017a), rural education (Harwood 2009; Yan 2003a), moral challenges (Kleinman et al. 2011; Wu 2010), and the spiritual wellbeing (Cooke 2009; Gao and Qian 2019). The shift from Maoist ideology of tight population control to the post-Mao governmentality indicates the changing governance of human life in China. The purpose is to push life beyond the survival of living beings to a level of adequacy and human flourishing (Zhang et al. 2010).

What constitutes a good life varies from context to context, from issue to issue, and from place to place. Kleinman (2006) explores the moral dimensions of human life, such as "how to live a moral life," "what moral experience entails," and "what really matters." 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 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 (2010), who analyzes 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.

Building upon these approaches, 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 2017; 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 life, such as dying within a care regime (Feldman 2017).

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 pursue 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 and the way to approach it might transform this nonpolitical project to a political project. 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 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 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 to achieve good life. 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 2010), 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 drawing a fine line between productive and repressive power, 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. These two lines of arguments are accountable when historical, cultural, and social factors are at stake. My intention in this chapter, however, is to examine conflicts that arise from different constructions of “good” care by state and non-state actors, even though each is constructive in promoting better social services in China.

In this chapter, 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 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 between certain forms of care and politics.

Creating a Systematic Eldercare Model in Shanghai

Building systematic care that is efficient, affordable, and accessible for each senior rests largely upon government. 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 the quantity rather than the quality of services. Preliminary eldercare programs—which include nursing home care, community-based care, and in-home care—are often implemented from the perspective of the service providers, instead of users.

Nursing home care is one type of eldercare service that the Shanghai government has invested a lot into. As of 2017, there were 703 nursing homes with 140,000 million beds total (SRCA 2017). These nursing homes primarily focus on daily-life support and offer basic medical care services by themselves or by outsourcing to collaborating medical institutions. There are also hospital-style nursing homes. This type of nursing home emphasizes medical care for elders. It has doctors, nurses, nursing aides, and basic physical examination equipment such as laboratory, CT scanners, rehabilitation equipment, etc. By 2017, there were thirty-nine hospital-style nursing homes. These two types of nursing homes are either public, private, or hybrid. Of the nine nursing homes I visited, three were public, four were private, and two were hybrid. Regarding service specialization, two of nursing homes focused on healthcare, while the rest mainly provided support for daily life.

While nursing home care is an important social service, community-based eldercare institutions have attracted the attention of seniors due to lower prices and easier access. Unlike nursing homes, which might be very far away from downtown, these institutions are often located within neighborhoods. There are two types of community-based eldercare institutions. The first are senior centers, which enroll independent elders or elders who need mild assistance. There were 560 senior centers in 2017 (SRCA 2017). The second type are mini nursing homes. Such facilities provide respite care for family caregivers, enrolling elders with mild functional disability or cognitive impairment, elders in need of rehabilitation services, and elders waiting for nursing-home beds. These mini nursing homes are small in size, with each providing between ten and 49 beds depending on the architectural structure. When I conducted my fieldwork in 2017, 127 mini nursing homes were functional, and more were under construction (SRCA 2017). These two types of community-based eldercare programs are typically hybrid. 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 mixed.

Home eldercare is the third component of the systematic care model in Shanghai. Historically, home care only limited to those three groups living without relatives, children, and financial resources. Yet, as life expectancy and potential eldercare burden continues to increase, home care has been expanded to include all seniors who meet certain criteria since 2018 (see below). Home care for seniors includes daily-life support such as chore services, meal delivery, etc. Other municipal eldercare programs provide regular home visits (e.g., the Senior Partner Project) and housing maintenance for elders with low incomes or those living alone. These social services are usually outsourced to local NGOs or governmental organizations, depending on each community's infrastructure. Elders who are eligible for these services are subsidized by government based on their economic circumstances.

The long-term care (LTC) project—which ensures the affordability of social eldercare services—is another significant mark for the development of dementia care in China. This project had an initial trial in Qingdao 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 administered service organization; and the Shanghai Municipal Health Commission provided necessary training and evaluation. Two categories of services were covered by LTC: in-home care and institutional care. These services mainly focused on daily-life support and basic medical care. Eligibility criteria for LTC services included: citizens aged 60 and above, and evaluated at the second level of disability or above.[24] For in-home care, three to seven hours of care services were organized weekly for recipients based on their disability levels. LTC covered 90% of the cost, and individuals paid the remaining 10%. For institutionalized care, LTC covered 85% and individuals paid 15%. The pricing strategies were 45 RMB/hour [$6.3/hour] for daily life support and 85 RMB/hour [$11.9/hour] for medical care in 2017. Considering the potential benefits for

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[24] 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.

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.

The systematic care offers an approach for the Shanghai government to professionalize dementia care. While nursing homes, community-based senior centers and mini-nursing homes, in-home care, and long-term care insurance are common in Western societies, 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. In order to deal with the increasing number of older population, a preliminary social system for eldercare is needed. While acknowledging this system indeed has paved the foundation for the further development of social services, the quality of care provided by this system often disappoints the public (Dong et al. 2008; Wang et al. 2018; Zhang 2017c). Particularly, dementia sufferers used to be excluded from the preliminary care system. Therefore, to build a systematic care that can provide professional services for dementia sufferers is both an indicator of a modern society and a sociopolitical achievement that the Chinese government aspires to. However, there is still a long way ahead.

Moral Worlds: Stigma, Dementia Sufferers, and Caregiving Burden

Before the Dementia-Friendly Initiative, family caregivers and dementia sufferers 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 2010-2013 and my field studies from 2014-2017, I found stigma made both dementia sufferers and their family caregivers susceptible to loneliness and isolation. Strategies against stigma include denial and keeping the diagnosis from outsiders. At times, family caregivers rejected any kinds of social support. In order to schedule a family visit, I often had to turn to the neighborhood committee for help. Otherwise, it was extremely hard to enter into dementia sufferers' households. When visiting them 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."[25] Family caregivers often had to place everything and everybody in the household in order. Often, I could see only two family members—the dementia sufferer and the caregiver. Other people 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 months' stay with this family, a constant topic we discussed was how to help elders with dementia since most of them refuse to take medication or receive any support. When I talked to 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 been captured by Lee (2019) in South Korea. This phenomenon also takes place in China where diagnosis with dementia means a social deprivation of one's moral status. Therefore, the denial of dementia is a rejection of their unworthiness and uselessness in late-life stage, which is often associated with power asymmetry between caregivers and care recipients. Even though Mo's mother was impaired on many aspects of her life, one

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[25] "Too old" traditionally refers to a life stage when one regresses to a status of childhood immaturity.

thing she was consciously aware of was the conversion from life-long caregiver to care receiver. When Mrs. Mo was absent, Mo's mother often lamented that: "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!" In China, loss of face means the loss of one's moral status and personhood, which 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. When family caregivers internalize the stigma, labelling effects go beyond dementia sufferers. 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. Because of associated stigma (Goffman 1963), family caregivers are frequently ambivalent about seeking social support. On the one hand, seeking support for dementia sufferers means that someone in the family has a mental disorder that is not socially accepted by others. On the other hand, family caregivers are the ones that have been worn out—emotionally, psychologically, and physically—due to their long-term care burden. The capacity for traditional family support is also tenuous. This is not only because of the rapid social transformation of Chinese society from the previous extended family to the nuclear family, but also due to associated stigma. During my fieldwork, I constantly 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 have to endure long-term depression, and some even commit suicide.[26]

Dementia Matters

Dementia care became a public issue in China only in recent years. In 2010 when I started working in a 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 families, and only one municipal nursing home enrolled elders with dementia. Most nursing homes rejected these sufferers 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.[27] In 2017 when I started my fieldwork, there had been a dramatic change. There were four NGOs specialized in dementia care and family

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[26] I have a separated chapter discussing dementia-related stigma in China.

[27] This is based on my work experience and my archival research during the fieldwork.

support. Many nursing homes listed dementia care on their service menu. Social organizations advocating on behalf of dementia sufferers 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; and the increasing number of people advocating on behalf of dementia sufferers and family caregivers (see Chapter 2).

State and non-state actors respond to dementia issues differently. The Dementia-Friendly Initiative, which is 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 skills of care workers. Consequently, the state mandates the professionalization of dementia services in the LTC project. The state also introduces the project of building dementia-friendly communities to ameliorate the stigma around dementia sufferers, and thus to facilitate their institutionalization. This model is characterized by dementia-care units and professionalization of services in dealing with 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 values such as filial piety and *ren* aims to improve the outcome of dementia services. These key elements contribute to a new vision of "good" care—relational care—which is valuable and inadequate in China. Within this framework, non-state actors seek to strengthen the relational dimensions of human life, which have been declining 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. Complying with global humanitarian ethics, this form of care highlights a new public culture in dealing with dementia sufferers.

While acknowledging the co-constructive relationship between the two versions of "good" care for the professionalization of dementia services, conflicts often arise when each stakeholder enacts different theories of "good" care into practice. Among these conflicts, two are identified. One is about investment debates, i.e., should we invest the dementia-care units or family-like institutional culture when there are limited resources? The other is about service professionalization debates, i.e., should eldercare institutions follow the state's rigid standards or do they have their own authority to decide how to practice "good" care? Although the discussion will not give an exhaustive portrayal of the features of "good" care, it demonstrates 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: Dementia-Care Units or Family-Like Institutional Care Culture?

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 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 first and 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 policy. 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. These dementia-care units aim to facilitate nursing-home administration. 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 which 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 management 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 rich 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 also judge the institutional care based on instruments and 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 fourteen years without any decubitus or hygiene 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!"

While acknowledging that infrastructure for nursing homes is necessary, the over-reliance on technology would lead to a substandard care. Instead of paying attention to the infrastructure, some nursing homes focus on the linkage 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. Combining Western humanitarian ethics and Confucian values, non-state actors generate a list of behavioral codes that challenge the dementia-care-unit model.

The first characteristic of relational care in the Chinese context is family-like institutional culture. While inclusiveness and person-centered care are based on Western conceptions of human rights, these norms in an institutional culture that values collectivism have a different denotation and practice. According to nursing home directors I interviewed, dementia sufferers should be included in all activities, and shouldn't be treated as a stigmatized group by constructing a separated dementia-care unit. Among the nine nursing homes I visited, two nursing home 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. According to the nursing home director Mrs. Pan, "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 way of addressing residents might surprise Westerners, but it is a culturally appropriate way to shorten the distance between caregivers and care receivers in the Chinese institutional context. Caregivers are treating their clients as family members, rather than consumers. Moreover, calling elders "grandma" or "grandpa" is also a Chinese way of showing respect for the senior status of their clients.

The second behavioral code in Chinese nursing homes is the expectation of continuing involvement of families after their kin are institutionalized. This differs from both Western counterparts (Kane and West 2005) and the dementia-care-unit approach, which often reduce dementia sufferers to consumer. In China, the primary caregivers for elders are family members, even though the eldercare industry is rapidly growing. 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 Xue’s perspective, doctors, nurses, nursing aides, and other staff helped families, rather than replacing them. In Xue’s nursing home, when he enrolled elders, he would ask families to come and visit them. He believed that, no matter how professional services were, their goal was supporting families. According to the traditional Chinese culture, parents raise their children, and when they are old, it is adult children’s responsibility to take care of them. Rapid modernization and the competitiveness of the job market have reduced the ability of children to devote themselves to eldercare. As a result, institutional care might be an option. However, “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,” Xue stated.

Nursing homes have different ways to make sure that families visit their elders. For example, some nursing homes make it a rule that families 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 advocate is creating a stigma-free environment. The four NGOs specializing in dementia care in Shanghai all engage in de-stigmatizing activities. Famous nationwide campaigns include the Yellow Bracelet Project, which aims to prevent people with dementia getting lost, and the Dementia Friends Project, which aims 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)," "shizhizheng (loss of wisdom)," etc., not be used in eldercare facilities. This official statement is an attempt to destigmatize the condition. However, its effect is limited to the sphere of eldercare facilities rather than the whole society. Therefore, non-state actors appeal for more public education with the hope of changing attitudes toward dementia. Mrs. Pan, a nursing home director, stated that: "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 often ignore local context.

While acknowledging that global humanitarian care ethics provide guidelines to develop dementia care services, to transform these services culturally appropriate requires the consideration of local practices and traditional norms. 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 the global 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 are, however, the lack of the transformation of global practices and the ignorance of culturally-appropriate services. These limitations generate more constraints when the state intends to professionalize how care should be practice, as I shall discuss below.

Service Professionalization Debates

Coupled with the project of building dementia-care units is the professionalization of services. Government officials, who emphasizes the quality control of services (e.g., rules, regulations, and standards), side with the systematic care. According to these 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 eldercare practices and the social and economic background of nursing aides. In contrast to the systematic care, non-state actors, especially nursing home directors, argue for a relational care that takes both nursing aides and care practices into account. According to these nursing home directors, 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 in 2017 intensified the conflicts between the governmental understanding of professionalism and non-state actors' practices of "good" care. This is because the Shanghai Quality and Technique Supervision Bureau constantly invades nursing homes to monitor the quality of care. Instead of checking the services provided to elders, this bureau requests that each nursing aide fills a complex form to record their work schedule every day. However, this form is complex and nursing aides spend too much time completing these forms. In turn, this reduces their work hours and affects the quality of services provided. When I visited these nursing homes, the government officials checked these forms in cursory manner. Some public nursing homes often hired someone to deal with the supervision; however, private nursing homes did not want to sacrifice the quality of care provided to their clients by favoring the governmental supervision. Therefore, many private nursing home directors complained about this rigid supervision. Mrs. Bai, a private nursing home director said: "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. Photo-taking ensures each senior receives a routinized service that has been documented. For example, a nursing aide has to take pictures when he/she feeds, moves, or changes a senior's diapers. This regulation, however, has nothing to do with “good” care; instead, it increases the workload for nursing aides. As a result, 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), felt even more frustrated. A nursing home director, Mrs. Yu stated: “I do not think our government understand 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 rapid policy changes regarding the competency of nursing aides further complicate debates about professional care. Previously, nursing aides had to obtain either medical care licenses or eldercare licenses to enter into the market. These two types of licenses distinguished the professional levels and authorized work domains that a nursing aid could provide, and thus determined their salaries. In order to control cost, many nursing homes preferred to hire those held eldercare licenses. Since the introduction of LTC, the Shanghai government requires that all nursing aides have to obtain medical care licenses to enhance professional care.

This rapid policy change has challenged the development of social care in Shanghai. First, it increases the cost of institutional services. According to Mr. Xu, previously hiring a nursing aide with an eldercare license cost about 7500 RMB [$1,050 USD] per month. But, 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 enforced transition from a loose policy whereby a nursing home could hire nursing aides with or without medical care licenses to a tight policy has reduced the number of nursing aides on the market. People might consider it is a temporary condition that can be solved by raising salaries. This challenge, however, 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. 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. Such situations were common in several other nursing homes. When I interviewed these 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 and the public discrimination toward nursing aides presents additional challenges to increasing the number of nursing aides. Although an exam is necessary to select well-trained nursing aides, the computer-based exam requires a candidate to have computer skills. Therefore, this exam rejects many qualified nursing aides simply because of their limited knowledge of computers. This is to be expected, however, since most nursing aides are mainly from rural areas and have limited access to computers. In Yu's nursing home, she and other staff had trained their nursing aides to use computers to pass the exam. Even though they had exerted a lot of effort, only twelve passed the exam, and six failed. Yu expressed her sadness about this rigid policy: "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, with higher educational levels, might not be willing to do a job that is considered as "dirty" and "unproductive" (Jervis 2001). Meanwhile, they are very close to the generation of the only-child who were born in the early 1980s. According to the public, the only-child generations are spoiled (Fong 2006) and refuse to do dirty work Therefore, this rapid 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. Research showed that most nursing aides were from remote, rural areas, with 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. Consequently, they had a very low professional reputation (Wang and Yuan 2018), including those who had successfully enrolled as professionals in LTC. In domestic settings, skeptical family caregivers often treat nursing aides as a domestic helper, regardless of their license status. They assign nursing aides to carry out household chores, rather than providing professional care to seniors. The main reason is that the public, and family caregivers in particular, do not trust nursing aides because of their "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 of nursing aides 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 in the relationship 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 their hosts, which could include being looked down upon and mistreated, some nursing aides prefer to work in institutions than domestic settings. 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 chapter traces 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 of power 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 nursing home 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 more 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 actually interface with each other in practice. The over-emphasis on professionalization of services without fulling taking the experience of nursing aides into consideration creates uncertainty on 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. When the state’s requirements are too high to meet, they will reduce the attention of nursing homes on their clients, and potential elder mistreatment can occur. 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 stigma because the establishment of dementia-care units separates 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 should work together to maximize social benefits. Strategies include integrating global humanitarian care ethics with traditional Confucian values, combining the systematic and the relational care approaches, and balancing the profit-drive purpose and person-centered care culture.

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 policymakers to learn useful information from practitioners and service users, and thus improve dementia care policies and administration in Shanghai and beyond.

Chapter 4 The Family Politics of Dementia Care: Decision-Making and Care Norms in Chinese Families

Introduction

In both industrialized and developing societies, families constitute the primary caregivers for elders who are physically or cognitively impaired. While acknowledging the cross-cultural similarities between practices of family support for elders, there are remarkable differences between expectations and values associated with eldercare. Eastern societies have venerated traditional Confucian values, e.g., filial piety, intergenerational interdependence, and gender roles in care practices. However, rapid economic, demographic, and sociopolitical transformations threaten traditional family structures around eldercare (Ikels 2004; Yan 2003b; Zhang 2017a). Sociologists and anthropologists have identified the power change between generations since the economic reform in 1978. These changes include the decline of parental authority and the increase of youth power in contemporary Chinese families (Davis and Harrell 1993; Ikels 2004; Yan 2003b). While acknowledging that rapid social change during the past four decades has indeed affected practices of filial piety in many parts of China, intergenerational support and interactions are still widely practiced (Yan 2016; Santos and Harrell 2017; Shea et al. 2020; Shi 2017a). This chapter will explore how the biopolitical governance—in the form of the state's legislation of family's responsibility for eldercare—affects each household's dementia care arrangements.

Even though families are the primary caregivers for elders, the dynamics of family structures and value-practice conflicts cannot be overlooked in modern China. Two basic aspects have puzzled researchers: intergenerational relationships and gender ideology. With regard to family relationships in China, social scientists have analyzed intergenerational dynamics in terms of exchange theory or reciprocity. Recently, Yan (2016, 2018) argues that the traditional patriarchal familism—which is parent-centered—has been transformed into a neofamilism. This neofamilism depicts a new family structure in some rural parts of China, in which the focus and meaning of life flow downward from the grandparents and parents to the third generation of grandchildren. Yan conceptualizes this neofamilism as descending familism, which ensures family solidarity by building upon intergenerational intimacy.

While acknowledging the significance of Yan's research, the concept of descending familism is historically contingent and limited in its context. First, most of Yan's research participants were in their fifties or sixties and in good health. Therefore, most of them did not need intensive eldercare and could continue to contribute to their families and society. Moreover, with an overall extended life expectancy, some members of this age cohort had surviving parents who might need intensive care. So, descending familism, which mainly focuses on the bottom layers of generations without examining the upper layers, cannot fully capture the family relationships in contemporary China. Second, an important context for the emergence of descending familism is the lack of social support around childcare (Qi 2018; Shi 2017a; Zhao and Huang 2018). However, the eldercare context is quite different from childcare, at least in urban China. For example, there is a preliminary social eldercare system in Shanghai, which provides various social services for the elderly in home settings, communities, and institutions. Moreover, the majority of elders in urban China have been covered by comprehensive healthcare insurance and social security. The availability of a preliminary social care system will not only affect family caregiving arrangements, but also shape new norms in contemporary China.

With regard to gender ideology, institutions and cultures have played a significant role in facilitating gender equality in China. During the Maoist period, the ideology of gender equality was prioritized by the state, and women were equally appointed to job positions in both rural and urban China (Li 2000; Jin 2006; Tsai 1996). Currently, more policies are being issued to ensure women's education and labor rights, which is significantly improving women's social and economic status (Xie 2013; Tao et al. 2004). Within domestic settings, compared to the traditional patriarchal family structure, some sociological studies argue that women have gained more decision-making power regarding their marriage partners, birth-control, divorce, and household labor division (Croll 1981; Davis 2010; Miao 1996; Shi 2017c; Zhang and Fussell 2017). However, another school of Chinese sociologists agree with Hochschild and Machung's portrayal of employed women as suffering from a double burden (1989): women are getting more involved in socioeconomic activities, while still taking care of household labor such as child care and eldercare (Palmer 2007; West et al. 1999). During my fieldwork, I found, within the domestic settings, there is a flexible gender ideology that falls between the traditional and non-traditional social roles. In terms of eldercare—as other developed countries have experienced—demographic changes have led to an increasing number of men taking on care work that has been traditionally assigned to women (Harris and Long

1999; Long and Harris 2000; Miller and Kaufman 1996). This strategic gender performance has been overlooked in previous studies of gender structures in China.

Taking gender ideology and intergenerational relations into consideration, I argue that rapid social transformations have changed raditional patriarchal familism into a negotiated egalitarian familism in urban China. While acknowledging that power asymmetry remains in Chinese families, the negotiated egalitarian familism recognizes both work duties of younger generations and rights of senior generations, as well as gender equality between males and females in domestic settings, which includes shared household chores and care obligations. By arguing for negotiated egalitarian familism, I do not mean to deny the broad gender inequality and asymmetrical relations between generations in Chinese society. Rather, I use this concept to draw attention to the changing context of family-based eldercare, in which modernization equally affects both males and females as well as older and younger generations.

In domestic settings, this egalitarian familism is evident in care arrangements. Traditional family structures are very clear-cut, and each family member has certain roles and rights. In terms of eldercare, sons should shoulder the primary responsibility, but in reality this obligation shifts to their wives. In other words, women do the majority of care work, even though it is assigned to men. As China has increasingly adopted Western values, the traditional family is transforming into a modern family with a focus on gender equality and intergenerational egalitarianism. Sociological studies have demonstrated the trend of egalitarian intergenerational relationships, in which each generation seeks individual freedom and autonomy, while sharing family eldercare responsibilities (Shi 2017a; Yang and Neal 2006; Zhang 2017b). As family relationships today tend to be egalitarian in principle, Chinese elders are generating new strategies to ensure care and support late in life. These strategies include self-care, daughters as caregivers, spousal care, and institutional care (Farquhar and Zhang 2005; Shea and Zhang 2016; Zhang 2006, 2017a). While the means are many and diverse, they also increase the possibilities for care recipients to make choices. Current trends in fertility, longevity, as well as family formation and division, continue to expand the range of these possibilities. Yet, little attention has been paid to the logic of these care choices, i.e., reasons and rationales underlying a certain care arrangement. When there is no specific need for care, Chinese families often maintain interdependence through symbolic occasions such as intergenerational exchange or mutual support. Therefore, it is significant to examine how individuals respond to family members in need of long-term care, such as dementia care. Investigating these decision-making processes is important because they reveal the specific values that guide interdependence and mutual support between generations.

This chapter aims to explore the family politics surrounding dementia care in Shanghai, China. Family politics in this chapter is defined as a set of activities to deal with the conflicts between gender equality and culturally-assigned gender roles, as well as the tensions between traditional patriarchal familism and modern egalitarian familism. This chapter explores the family politics of dementia care through the following research questions: Who has the power to affect eldercare arrangements in domestic settings? How do relationships between caregivers and care recipients influence, and become influenced by, rapid social change? How are prevailing gender attitudes and changing gender roles affected by the practice of dementia care? How do dementia care arrangements reflect traditional and modern gender ideologies in contemporary Chinese families? By focusing on family caregiving for elders with dementia in Shanghai, this chapter provides insights into changing family structures and relations, gender ideologies, and eldercare norms in contemporary China.

Basic Statistics of the Study Sample

The data were deriving from in-depth interviews with 38 family caregivers in a residential community, and 106 family caregivers in a memory clinic. All family caregivers and care recipients have their household registration (*hukou*) in Shanghai. Table 1 shows that the majority of care recipients were aged 66 and above, and almost half of these care recipients were aged 80 and above. Females, as other studies indicated in urban China, had a higher dementia incidence rate than males.

Table 1. Age Cohorts of Care Recipients by Gender

Age range	**Male**	**Female**	**Total**
=<50	0	0	0
51-55	1	1	2
56-60	2	1	3
61-65	3	3	6
66-70	8	13	21
71-75	12	14	26
76-80	6	12	18
>=80	22	46	68
Total	54 (45.2%)	90 (54.8%)	144 (100%)

In this chapter, I argue that a negotiated egalitarian family politics of dementia care is emerging in Shanghai. First, there is gender equality in dementia care arrangements. While acknowledging that females constitute the primary caregivers for dementia sufferers, there is an increasing number of male caregivers. Table 2 shows an almost equal share of care responsibility between male caregivers (45.2%) and female caregivers (54.8%). Traditionally, elderly parents would live with a married son. In Table 5, we can see that in 22 cases parents lived with a son (in 7 cases care recipients lived with a spouse and their son and in 15 cases care recipients lived with a son only), while 27 seniors chose to stay with a daughter (in 14 cases care recipients lived with a spouse and their daughter and in 13 cases care recipients lived with a daughter only). Among those 71 cases involving both daughters and sons, in 25 cases care recipients chose to live with their spouses only, in 11 cases care recipients lived alone, in 17 cases care recipients lived with their daughters, and in 18 cases care recipients lived with their sons. These living arrangements reveal changing living patterns with adult children, which reflects a more gender-equal opportunity for senior parents to stay with their children. The increasing number of male caregivers getting involved in care practices calls attention to the transformation of gender roles in China. For male caregivers, there is a broad age range, from the youngest caregiver aged 28, to the oldest caregiver aged 91, and with a median age of 69. Moreover, two thirds of both male and female caregivers were aged above 61, indicating that most caregivers were elderly themselves (also see Shea and Zhang 2016). The increasing amount of eldercare performed by elderly men draws attention to the linkage between caregiving discourses and the continuing changes in gender roles in urban China.

Table 2. Age Cohorts of Caregivers by Gender*

Age range	**Male**	**Female**	**Total**
=<50	2	4	6
51-55	7	7	14
56-60	3	9	12
61-65	7	15	22
66-70	8	12	20
71-75	10	12	22
76-80	8	5	13
>=80	13	6	19
Total	59(46.1%)	69 (53.9%)	128 (100%)

(*Care recipients who ended up self-care or institutional care are excluded from calculations here)

The second dimension of egalitarian familism in dementia care is a hierarchical care pattern: spousal care first, adult-child care second, and paid care last. This hierarchical care pattern coincides with the Western "hierarchical compensatory model" proposed by Cantor (1979, 1991). This model formulates a hierarchy of preferences of elders in need of care: close relatives first, friends and neighbors second, and formal services as the last resort.

In Shanghai, conditions governing the provision of family care to the elderly include proximity, availability, and financial resources of both care recipients and family caregivers. This study found that most care recipients were cared for by their spouses (also see Zhang and Shea 2016), as indicated by Table 3.

Table 3: Care Arrangements for Elders with Dementia by Gender

Care arrangements	**Males patients**	**Female patients**	**Total**
Spousal care only	36	29	65 (45.1%)
Mixed care (spouses & home aides)	1	3	4
Mixed care (spouses & one adult child)	5	5	10
Mixed care (spouses & adult-child rotation)	1	4	5
Mixed care (spouses, adult-child rotation[28] & home aides)	1	1	2
Self-care	1	6	7
Self-care and home aides	1	1	2
One adult-child care only	2	24	26(18.1%)
Mixed care (one Adult child & home aides)	2	4	6
Mixed care (adult-child care rotation)	0	7	7

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[28] Adult-child rotation care is a care arrangement, in which several siblings share the burden of eldercare. One such shared solution is rotating residential arrangements among adult children.

Mixed care (adult-child rotation & home aides)	0	3	3
Nursing home care	4	3	7
Total	54	90	144

Among the 144 families, 86 spouses (59.7%) involved in caregiving and 65 (45.1%) spouses were the solo caregivers for their partners. The preference for spousal care can be explained by the fact that a high proportion (50.5%) of elders were married and living with their spouses, as shown in Table 4.

Table 4: Care Recipients' Living Arrangements by Gender

Living arrangements	**Males**	**Females**	**Total**
	N=57	**N=87**	**N=144**
Living with spouses			
Only	40	33	50.7%
&unmarried /divorced children	3	5	5.5%
&married children	6	7	9.0%
Living without spouses			
Alone	5	17	15.3%
&unmarried/divorced children	0	7	4.9%
&married children	3	18	14.6%
Total	57	87	100%

Adult-child care takes a secondary place in this hierarchical care pattern. Twenty-six cases fell into this category, approximately 18.1%. Compared to Ikel's study in 1990s in Guangzhou, in which the majority of elders were living with and cared for by their adult children (1993), this study found that adult-child care plays a secondary role due to the unavailability of adult children. Table 5 shows that about 30% of care recipients had only one child, which makes adult-child care a limited resource for eldercare.

Table 5: Care Recipients' Living Arrangements by Gender of Surviving Child(ren)

Living arrangement	**Has 1 son**	**Has sons>=2**	**Has 1 daughter**	**Has daughters >=2**	**Has both**	**Has none**	**Total**
with spouse only	11	12	18	7	25	0	73
With spouse and son	1	0	0	0	6	0	7
With spouse and daughter	0	0	4	2	8	0	14
With son only	1	2	0	0	12	0	15
With daughter only	0	0	4	0	9	0	13
Alone	1	1	2	5	11	2	22
Both	0	0	0	0	0	0	0
Total	14(9.7%)	15(10.4%)	28(19.4%)	14(9.7%)	71(49.3%)	2(1.4%)	144

Given the unavailability of adult children, some families—if their financial resources allowed—would hire in-home aides to do care work, or go directly to qualified nursing homes. Table 6 shows the retirement pensions of both care recipients and caregivers. Almost one third of caregivers and care recipients had a monthly income of more than 5,000 RMB [$700USD] either through pension or wages. This was much higher than that in other parts of mainland China.[29]

Table 6. Retirement Pension of Caregivers and Care Recipients

Pension range (RMB[30])	**caregivers**	**Frequency (%)**	**Care recipients**	**Frequency (%)**
<3,000	13	9.7%	13	9.0%
3,000-4,000	33	24.6%	61	42.3%
4,000-5,000	42	31.3%	24	16.7%
>5,000	46	34.3%	46	31.9%
Total	134	100%	144	100%

In addition to gender and intergenerational dynamics demonstrated above, a third perspective through which to examine family politics is the trajectory of care arrangements over time. Although this project is not a longitudinal study, the variety of

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[29] The latest official annual report of the average retirement monthly pension is the 2016 China Labor Statistic Annual Report. http://www.mohrss.gov.cn/SYrlzyhshbzb/zwgk/szrs/tongjinianjian/201803/t20180302_289122.html, access 09/09/2018. Based on this report, the average monthly pension in Shanghai was about 3377 RMB in 2015. This was calculated by the total expenses of urban and rural areas of Shanghai (2035.2 million and 48.4 million RMB) and the total retirees in both urban and rural areas of Shanghai (4.654 million and 0.487 million). Other unofficial report about the average monthly pension of Shanghai retirees was 3754 RMB based on the recent policy on pension in 2017. See http://news.ifeng.com/a/20170825/51753519_0.shtml.

[30] 1 RMB =0.14 USD in 2019.

care arrangements can give us a brief understanding of transitional care patterns. In Table 3, in addition to the 65 cases of sole spousal care and 26 cases of sole adult-child care, nine cases belonged to the category of self-care, seven cases fell to the category of nursing home care, and the remaining 37 cases ended up with mixed care. The transitional care pattern in urban China is similar to that of the long-term care system in the U.S. (Kane and West 2005). As physical or cognitive abilities decline, an older adult usually attempts self-care, turning next to their families, then to assistive care, and finally to institutional care. Yet, compared to the robust social care systems in the West for elderly people, in China, large numbers of seniors in need of care seek support from their families. Therefore, a large portion of the care trajectory takes place in domestic settings, as evidenced by the various configurations of mixed care in Table 3. Due to the limited space in this chapter, I will focus on the discussion of solo spousal care and solo adult-child care.

From the statistics, we can see that dementia care arrangements are structured according to a seemingly egalitarian familism. However, these statistics alone cannot fully capture the complex and dynamic nature of family structures in eldercare. I argue that this set of family politics serves as a guideline, stipulating the criteria that must be considered in the distribution of family responsibilities, rather than what should be done in a specific situation. Moreover, the application of this family politics is negotiated according to circumstances in which social structure and individual agency are taken into account. Therefore, the organization of dementia care is shaped by both family politics and contingency. Factors beyond the principles of family politics include structural elements such as housing reform[31]; the state promotion and legislation of family responsibility; the development of the eldercare industry and social security; Western values emphasizing autonomy and gender equality; and capacity for individual agency.

The following sections unravel the decision-making processes and the underlying logics of dementia care arrangements. I discuss the logics of each care arrangement and associated factors that contribute to a specific dimension of family politics of care. I also pay attention to how the intensive dementia care affects the decision-making in terms of intergenerational relationships and gender roles. Lastly, I offer a brief discussion about the family cultures of dementia care in Shanghai, China.

Contextualized Decision-Making Processes: Spouse-Dominated Care

Decision-making processes involve rationales associated with the organization of care work in domestic settings, i.e., who does the care work and why? In addition to the proximity, availability, and the financial circumstances of both care recipients and family caregivers, spouse-dominated care is due to the intimacy-based or instrumental-oriented conjugal relationships. These rationales further contextualize the decision-making processes of spouse-dominated care, in which spouses are the primary caregivers.

Intimacy-based Care

Intimacy-based care refers to the continued conjugal love between spouses after the onset of dementia. Such caregivers view dementia caregiving as part of their daily life and the onset of dementia does not affect care recipients' role in the household. In traditional

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[31] The housing reform has not only privatized public housing, but also transformed its nature from being a basic necessity during the Maoist China to a commodity that is beyond the affordability of average households in capitalist China.

Chinese culture, conjugal love is almost like a taboo that should not be mentioned in public. In a country going through rapid transformation, notions of conjugal love have begun to take on new meanings in China (Shea 2020). While most research focuses on conjugal love among younger generations, this study found that conjugal love late in life remains an important element for older people, e.g., intimacy-based care.

In my research, the most visible intimacy-based care is the direct expression of their life-long conjugal love and responsibility. It is the intimate relationship that enables these spousal caregivers to do whatever they can during caregiving. The 91-year-old man, Mr. Liu (#W02), had been taking care of his wife for almost twenty years. He attributed his compassion for caregiving to their conjugal love. During the interview, I learned that this couple was engaged when they were extremely young: Mrs. Liu aged five and Mr. Liu aged eight. Even though it was an arranged marriage, they ended up a happy relationship. According to Mr. Liu, they had never quarreled with each other throughout their life. No matter how hard life was, they were able to find love from each other. Pointing to a picture in which the couple held hands, Mr. Liu felt satisfied with their relationship: "What does it mean? Holding hands till the end of our lives! (laughing)." Unlike other senior caregivers who often lamented their past difficulties and how this disease had changed their lives, Mr. Liu expressed his gratitude when his wife smiled at him each morning.

This intimacy-based care does not necessarily depend on intergenerational support. This couple had five daughters, two of them living abroad, and three in China. Unlike other seniors, Mr. Liu did not expect their daughters to take care of them, nor did he financially support them after their college education. In order to enhance their quality of life, Mr.

Liu made a monthly budget to balance their pensions and expenditures. In the budget, he spent about 4,000 RMB [$560USD] for hiring a home aide to support his caregiving; about 2,000 RMB [$280 USD] for daily necessities; about 2,000 RMB [$280 USD] for travelling; and another 2,000 RMB [$280 USD] for healthcare. After these expenditures, Mr. Liu told me that he still had some savings for emergency care. When I asked him whether it was his financial independence that made them happy, he indeed acknowledged that but he also mentioned his “modern” thoughts, i.e., the consumption mindset. Mr. Liu said, “Previously I always saved money. But when I saw that my colleagues died without the opportunity to improve their quality of life, I changed my mind. I start to spend money on whatever I like.”

Conjugal love becomes very precious when economic circumstances do not allow family caregivers to spend money on whatever they can. Mr. Wang (#069) had been taking care of his wife for about five years. His wife’s dementia conditions progressed very fast in this short period of time. At a relatively young age of 70, Mrs. Wang had lost her ability of continence. What made life even more difficult was that their only child, Junior Mr. Wang, quit college six years ago. He had been jobless because of his depression. Basically, Mr. Wang had to take care of both. Because of their limited pension and the enormous expenditure on healthcare, Mr. Wang was very thrifty. When I asked him about the possibility of institutional care, Mr. Wang expressed that their economic conditions would not allow them to purchase quality care:

> Our pensions are about 8,000 RMB [$1120 USD] per month. We have to spend about 2,000 RMB [$280 USD] on healthcare for my son and my wife. I have calculated enough to make sure we spend about 2,000 RMB

> [$280 USD] on our daily necessities. I also have to pay my son's health insurance and social security every year. It's also a big expenditure. So, we cannot save much after all costs.

Even living with difficulties, Mr. Wang expressed his love toward his wife. In our conversation, I learned that this couple was engaged before the Cultural Revolution when they were college students. During the ten years of chaos, they were forced to separate from each other in remote areas. It was after the Cultural Revolution that this couple could get reunified and married. When Mr. Wang recalled their past experiences, he felt the current difficulties were nothing since they could see each other:

> We have been married for more than thirty years, and I, at least, have to take this responsibility. Since I married her, I have to take care of her, no matter in illness or health. We are just getting old and will die together. She used to go out and get lost. But now she knows to hold my hand. The weather is extremely hot these days, and I still let her hold my arm, despite the hot rashes on my arm. We are like Liang Shanbo and Zhu Yingtai [a couple of mythical lovers in ancient China], always holding hands.

Mr. Wang used a famous, tragic love story in ancient China not only to express their conjugal love, but also to project their sad fate—two lovers who could not fully love each other because of social barriers. These barriers were the Cultural Revolution when they were young, and the illnesses of their loved ones when they were old. Even so, Mr. Wang maintained a positive attitude since they could now see each other every day. His satisfaction with such simple fact—to see each other every day—depicts their deep love, regardless of illness or health.

In addition to direct verbal expression, spousal caregivers often describe their conjugal love in detailed practices during caregiving, such as being generous, attentive, and patient to their spouses. Since his wife was diagnosed with dementia, Mr. Ding (#026) started to prepare good food for her. When I asked him what kinds of good food he prepared, Mr. Ding smiled to say "meat." Since his wife liked braised pork, a local cuisine in Shanghai, he cooked it every day. Mr. Ding further explained, "Previously, having braised pork only happened on holidays in the past. Now, we can afford to eat it every day. She has been thrifty for her whole life, and she is the person who can share weal and woe in life. I appreciate her and want to cook better food for her." While husband caregivers tend to be more money-wise, wife caregivers can be more attentive to their husbands. Mrs. Yang (#014) who was taking care of her 65-year-old husband, expressed how attentive she was: "Even though I am not good looking, I am tender-hearted. On the way to hospital, I kept talking to him, and told him this road was *Deping* Road where he got dental care, this road was *Yanshen* Road where he worked, so on and so forth." Because of flexible gender roles late in life (as I will discuss in later sections), some husband caregivers are also very attentive to their wives. Since Mr. Zheng's (#099) wife became incontinent, he had to constantly remind his wife to go to the bathroom. After using the toilet, sometimes, Mrs. Zheng forgot to clean herself. Mr. Zheng would remind her and if she could not understand it, he would directly do it for her. Unlike other kinds of care relationships in which body contacts often result in contamination (Foner 1994; Jervis 2001), conjugal love is strengthened when these intimate physical contacts become frequent in caregiving. These bodily contacts constantly remind spouses that they are needed. Thus, care is seen as a natural part of their relationship.

Instrumental-based Care

Contrary to intimacy-based care, instrumental-oriented care means spouses focus on the associated problems with dementia and their solutions but without explicit reference to the conjugal relationship. Caregivers who are instrumental-oriented pay close attention to whether and how their care practice can support their partners to live independently (together as a couple), and thus to minimize the influence on other family members. Compared to intimacy-based care, rationales of instrumental-oriented care can vary from case to case. There are push-and-pull factors shaping this practice. Push factors, such as poor intergenerational relationships, the unavailability of adult children, and the onset of dementia itself, are included. Pull factors, such as the feeling of being able to continue to contribute to the extended family, have been mentioned frequently. Due to these factors, spouses become the primary caregivers for their ill partners.

Sometimes, spouses become the primary caregivers when their adult children fail to show filial piety to their parents. Mrs. Zhu (#W34) had been taking care of her husband for more than six years. This couple only had one child, their daughter. Unlike the ideal close mother-daughter relationship (Shi 2017c), Mrs. Zhu had a tense relationship with her daughter. According to Mrs. Zhu, her daughter, even though she lived very close to this couple, had never contributed to caregiving:

> I cannot get along with my daughter. She never comes over to visit my husband. She complains about us being dirty and does not allow me to use her washer. She throws out things she dislikes and puts leftovers into trashcans. She wants everything new but does not work enough. I cannot tolerate her behaviors. I have suffered a lot for taking care of my husband,

> and now she completely breaks my heart. How can I rely on her? Sometimes, I would cry at midnight, and then I was too tired to cry. I will go out and buy some litchi to cheer me up. After all, I have to take care of him. If my health conditions get worse, he will suffer more.

The case of Mrs. Zhu demonstrates the contending values between the older and the younger generations in one family. While the younger generation is often self-centered and endorsing consumerism, the older generation values intergenerational dependence and frugality. These contending values often create family conflicts and senior parents have to relinquish the fantasy of adult-child care and support. After witnessing so many adult children who fail to show filial piety, seniors turn to those who share similar values, i.e., their spouses, for mutual care and support late in life. In a remarried family, the husband, Mr. Jiang (#W05), who was taking care of his wife, also complained about the reluctance of adult children to take responsibility for eldercare. Mrs. Jiang had three children with her ex-husband. However, none of them wanted to take care of her when she was diagnosed with dementia. According to Mr. Jiang, they did not even show up when their mother was hospitalized:

> The senior daughter is in her sixties, retired, divorced, and has a son. She does not have enough money, so she has remarried and continues to work. The middle son is also not reliable. I called him several times when she [Mrs. Jiang] was in hospital. He did not even answer my phone originally. When he knew that, he came over here for ten minutes and left. The youngest daughter, even though she knows to take care of her mother, has never done household chores. She is busy sightseeing and playing. She

> even hires two home aides to do her household chores. How can you rely on these children? So, after looking around, we have to rely on ourselves and our spouses for care.

Unlike those spouses who are intimacy-oriented during caregiving, some care recipients turn to their spouses because of adult children's reluctance to provide instrumental care, which in turn reinforces the significance of spousal care late in life. Because of the different values across generations, e.g., the pursuing of individual benefits and personal pleasures, some adult children do not prioritize the needs of senior parents. In response, family structure has to modify itself to meet their needs, such as remarrying late in life or increased and prolonged mutual support between spouses.

When adult children are the only-child of their parents and have work-care conflicts, spousal care becomes critical to maintain family functions. Mr. Lu (#093) was taking care of his wife. In addition, Mr. Lu had to take care of his grandson because his only daughter was busy with work. His daughter and her husband were lawyers and had to travel each week and often stayed home less than three days a week. The lack of caregiving resources forced Mr. Lu to learn driving in his sixties and then cooking in his seventies. Mr. Lu was consciously aware of his instrumental roles in family management and said, "If I was sick or died, it would be a difficult situation since no one would be able to take care of my wife and grandson."

In urban China, the development of the market economy has brought not only an open society, but also overwhelming work stress on the younger generations.

Some adult children, especially those who retired early due to the bankruptcy of their work units, have to continue to work after their retirement. Realizing the work requirements of adult children, some seniors often relinquish the expectation of adult-child care. Mrs. Zhao's (#W19) two children had to continue to work in their fifties because their pensions were lower than others in Shanghai. She expressed that she would continue to take care of her husband if her health condition allowed her to do that. If not, they would consider institutional care, rather than adult-child care.

The geographic division of family members also drives spouses to mutually support each other late in life. Many youths in Shanghai choose to stay or work overseas, so the responsibility of taking care of elderly parents can only be shifted to the elderly themselves. Among the 144 families, about twenty had children abroad who could not take care of their parents. Mrs. Chen (#060) was taking care of her husband. This couple had two sons, with one in Canada and the other in New Zealand. Although their children invited them to stay with them, they did not like the daily life in other countries. Mrs. Chen said, "We are in our eighties and could not travel too far away from home. We can use WeChat to contact each other, but staying in a foreign country is not our preference. Gradually, we got used to the spousal care."

Some other push-and-pull factors that drive spouses to be caregivers include the illness of dementia itself (e.g., the inability to recognize people around) and the poor health conditions of adult children. In some cases, the onset of dementia forces spouses to be the primary caregivers because patients do not like "strangers" at home. Mr. Xia (#020) and his wife who was suffering from dementia were in their eighties. They had three children, but two were in the US, and only their daughter was in Shanghai. Originally, Mr. Xia thought their daughter could provide support for their eldercare. He gave up this expectation because his daughter was suffering from severe diabetes, obesity, hypertension, and other chronic illnesses. What made their care even more challenging was that Mrs. Xia did not like “strangers” at home, including their son-in-law. Therefore, it was impossible for the two generations to live together, nor would it be possible to hire a home aide. Mr. Xia said, “She is a strange person. When she saw our son-in-law, she would yell at him; when she saw the home aide, she thought we had an affair and would not stop yelling at her. There is no other solution. I have to take care of her alone because she only knows me.”

Two rationales drawing on different discursive and emotional repertories—instrumental-oriented care and intimacy-based care—are derived from the marital relationship. These two rationales are not mutually exclusive from each other; in reality, each reinforces the other. Rationales for spouse-dominated care include not only the love and moral obligation in conjugal relations, but also how it benefits both the younger and the older generations. Realizing the contending values between generations, senior parents actively deploy their financial resources to organize care that can either reinforce their conjugal love late in life or continue to play an instrumental role for their families.

Decision-Making Processes: Adult-Child Care

Although spousal care is a preferred practice over adult-child care in Shanghai, at some point, widowed elders and senior spouses who are too weak to support themselves will turn to their children for help. Traditionally, adult-child care is structured by the Confucian value of filial piety. Rapid modernization has transformed the meanings associated with adult-child care. In practice, rationales of adult-child care differ remarkably. Two logics were identified guiding the adult-child care: parent-primacy care and negotiated care. In this section, I will contextualize the decision-making processes of adult-child care.

Parent-Primacy Care

Parent-primacy care is based on the traditional filial piety yet differs in terms of the power structure between generations. Adult children adopt parent-primacy care because they prioritize parents' needs, but they do not necessarily need to show obedience or submission. It is the moral imperative that drives them to shoulder family responsibility. Among the 44 adult-child caregivers, 17 were subject to the logic of parent-primacy care, including five singleton caregivers, three caregivers who had overseas siblings, six sibling rotation-based caregivers, and three caregivers who assumed the primary care responsibility for the sake of extended family.

For the singleton caregivers, they have to show their filial obligation because of public attention. Mrs. Xue (#W07) was an adopted daughter, and her mother's dementia conditions became severe recently. In order to fully devote herself to care, she quit her part-time job. Mrs. Xue explained:

> People will gossip if I send her to a nursing home. They all know that I was adopted, and it would be harder for me. Since she [my mother] gave me all her money and housing property, I have to do by myself. If not, they will gossip behind your back. The TV show, *Laonianjiu* [Old Uncle], often discusses these issues.

Although the influence of public opinion and gossip has decreased during the process of modernization in China, in traditional communities where neighbors all know each other, it remains an effective moral instrument to monitor people's behavior. *Laoniangjiu* is a popular TV program among older generations in Shanghai, which focuses on proper protection of seniors in both domestic settings and society at large. The moderator is a famous senior woman who voluntarily regulates family disputes. This program constantly reminds both younger and older generations that taking care of elders is not only a moral responsibility but also a legal obligation.

The singleton generation also has to show their filial obligation when they have no siblings or other relatives to share the responsibility. Ms. Kang (#040), aged only 28, had become a caregiver for her mother who developed dementia after a surgery. Unfortunately, her father passed away when she was very young. It was her mother alone who raised her in Shanghai. Their relatives all became estranged because they were very poor. Because of her mother's long term sacrifice, Ms. Kang quit her job to take care of her mother. "My mother has been always in a low mood. I understood her depression when we were extremely poor. Now, our life has become much better, but she is still unhappy. If I resign my obligation, she will have no hope for life. I have to take care of her," said Ms. Kang.

Some family caregivers prioritize their parents' needs because they share similar values. Mrs. Wang (#059) and her brother took turns to take care of their mother. Unlike other families that often had conflicts among siblings, Mrs. Wang and her brother had a good sibling relationship because they both endorsed family's responsibility for eldercare. When her mother got sick, Mrs. Wang decided to retire, even though her work unit wanted her to continue to work. In our conversation, she explained, “I only have one mother, and I want to take good care of her. My parents are my Heaven [*tian*], if they both die, life is meaningless.” The prioritization of parents’ needs is also evident in her brother’s behaviors. Mrs. Wang continued, “He joined me in caregiving immediately after his retirement. When he saw me tired, my brother asked me to go home for rest. His wife is also nice and often cooks food for my parents. My husband, too, always let me rest at home. My son is 30 years old and has not married yet. After seeing my caregiving, he told me to bring his grandparents to our home. Overall, our family is harmonious and full of love.”

Endorsing religious beliefs facilitates this value-based care. For instance, Mr. Zhang and his sister (#106) as well as their families were all Buddhists, which made them easier to take care of their mother. They did not want their mother to go to nursing homes. Instead, they tried their best to do caregiving by themselves. Mr. Zhang’s mother stayed with him after his father died. Even though Mr. Zhang and his wife still had work duties, they took the majority of care tasks. His sister, who had retired, assisted his brother with care tasks when he was absent from home. Mr. Zhang told me how they organized care, “My wife prepares food for us, and the leftovers are for my mother’s lunch. My sister comes over at noon to heat the food and prepare some snacks for her. In the afternoon, they talk for a while. After work, I come back home and if I have time, I will accompany my mother to read and write Buddhist scriptures.” When I asked Mr. Zhang and his sister how they could harmoniously deal with their mother’s needs, Mr. Zhang stated, “We try our best not to make her feel lonely after my father died. I feel that our mother—a Buddhist—is a blessing for us.”

Adult-child caregivers who endorse parent-primacy care also show their moral superiority in the society. When I expressed that it was rare to see adult children who prioritized their parents' needs, they all agreed with me about the decline of filial piety in contemporary Chinese society. Moreover, they expressed their moral superiority when their behavior differed from others. Mrs. Fu (#032) had been taking care of her mother for about three years. When her overseas sister expressed the sadness about dementia caregiving, Mrs. Fu felt it was her responsibility to take care of their mother. She further expressed her motivations for caregiving: "We are all Communist Party members in our family. We care about family face [reputation]. My mother lives in a big house for cadres. We cannot treat her poorly to bring shame on our family and other people living there." While acknowledging the communist moral code facilitates their priority of parent's needs, the moral superiority in turn reinforces their endorsement of this belief.

This moral superiority can also be found in average families. Mr. Li (#028) and his two siblings took turns caring for their mother. The parents of Mr. Li were sent-down youth in Xinjiang (a Northwest province in China), and it took them almost thirty years to return to Shanghai. During this period of time, Mr. Li and his two siblings all grew up in Xinjiang. When they returned to Shanghai, they felt that "people do not care about each other very much here. They all seek personal benefits, and even leave their parents unattended." On the contrary, Mr. Li remarked that their extended families had a deep *qinqing* [family affection], which made them different from most families in Shanghai. Because of their family bonding, Mr. Li and his siblings did not quarrel with each other. According to Mr. Li, each contributed to their mother's care based on individual economic circumstances. For instance, Mr. Li's sister was divorced and later had a car accident, he did not ask his sister to financially support their mother; instead, Mr. Li actively shouldered his sister's daughter's education costs. Mr. Li's brother also had difficulties because he had limited education and lower salary. He had to continue to work after retirement in order to support his son's college training. Mr. Li also financially supported his nephew occasionally. While Mr. Li was financially well-off and helped other family members, his two siblings also took care of their mother when Mr. Li traveled for business. "It is our family affection that makes me feel we are human beings. Otherwise, we are no different from animals," Mr. Li said. While his words are indeed too strong to express his value of familism, Mr. Li's prioritization of his parent's needs both demonstrates his disappointments with and moral resistance toward the rapidly changing society.

Comparing to filial piety, parent-primacy care continues to be characterized by reciprocity and sacrifice over a strong sense of interdependent network of kin. As with Latina cultures that endorse familism (Flores et al. 2009), Chinese caregivers who side with parent-primacy care stress their adjustment after the onset of dementia of their loved parents. Adjustment means the possibility of exchanging one's social responsibility with family eldercare responsibility, such as quitting one's job and requesting an early retirement. The adjustment might take place within boundaries defined by the traditional Confucian value *baishan xiao weixian*, which places filial piety as the foremost goodness among hundreds of good behaviors.

Unlike traditional filial piety with a strict patriarchal order, parent-primacy care is a multidimensional construct, which involves public opinions, family circumstances, and individual responsibility. Although adult-child caregivers' narratives about parent-primacy care are not consistent, they all point to the fact of being attentive to needs of elderly parents, rather than being obedient in a traditional hierarchical sense. There might be some overlap between parent-primacy care and traditional filial piety in terms of practice. However, relationships between caregivers and care recipients have been modified to fit into modern society that values individual responsibility and intergenerational egalitarianism, rather than patriarchal orders. Some adult-child caregivers who are attentive to needs of senior parents are often collectivistic oriented and often take eldercare as a moral practice that differentiate themselves from the rest of society. The moral superiority makes their care practices a kind of resistance to the rapidly changing society, rather than simply endorsing filial piety.

Negotiated Adult-Child Care

A new established norm—family responsibility for eldercare based on inheritance rights—has transformed the traditional practice of adult-child care. Contrary to parent-primacy care, in negotiated care, adult children believe that the allocation of family responsibility should correspond with property inheritance rights. In Shanghai, the most valuable property is housing. In my previous study, I discussed a property-inheritance based care pattern (Zhang 2017c). Older generations today have been sufficiently resourceful of fortune in terms of housing property, which has become an important asset worth fighting over with other family members (Davis 2010; Zhang 2017c). Unlike previous older cohorts who had limited financial resources and often relied on their adult children for late-life care, most elders in contemporary urban China have their own pensions, which enables them to be financially independent from their children. During my fieldwork, I found some elders living with their adult children choosing to share daily expenses or financially support their adult children. Moreover, most elders have their own bank accounts, and they manage their property themselves until they completely lose the ability.

Elders with sufficient resources in Shanghai have alternative strategies to negotiate with their adult children on eldercare. Regarding the 44 cases who are solo adult-child caregivers, 22 cases received benefits from their parents, either in the form of a retirement pension and savings, or in the form of housing property; and five cases were negotiating care arrangements and divisions of housing property when I conducted my research. Moreover, among the 22 adult-child caregivers, nine sons and seven daughters inherited the exclusively large portion of property from their parents, and the remaining six caregivers received equal proportions of property with their siblings.

The process of negotiating eldercare responsibility and inheritance rights in some families can be peaceful and an agreement is easy to achieve. Mrs. Lv (#062) was a solo caregiver for her mother. She was also the one taking over her mother's housing property, even though she had four siblings. Mrs. Lv explained to me their agreement:

> When I got married, I moved out. But later my husband and I moved back and lived with my mother because my in-laws' housing was in a poor condition. My mother also got along with me and my husband. Because we have stayed with my parents for so many years and my siblings all have their own houses, my mother's housing belongs to me and I take care of her. They [siblings] also agreed. But, according to our agreement, if I ask them to come over, they have to help. But I rarely do that since my husband can help me.

The peaceful relationship among siblings is achieved when parents have a clear statement on the one hand, and adult children have similar economic circumstances on the other. However, not every sibling relationship can deal with property rights peacefully. Some cases end up with broken family ties when senior parents assign their housing to their preferred child. Mr. Zha (#054) had been taking care of his mother for more than ten years. He had a brother who had immigrated to the US and a sister who lived in Shanghai. When his mother gave her housing and pension to him, Mr. Zha became the solo caregiver. According to Mr. Zha, his two siblings rarely came back or contacted him since their mother made the decision, even though there were no obvious family conflicts. Mr. Zha did not feel there was something wrong when I asked him about his solo caregiving status. Rather, he tried to convince himself by stating that, "[I] just think of myself as the only child."

The new norm of establishing family responsibility for eldercare based on inheritance rights also impact a group of people in Shanghai, i.e., the sent-down youth. Sent-down youth were a group of people who left their hometowns and work in rural areas from the 1950s to the end of the Cultural Revolution. Since 1976, some sent-down youth gradually returned to their original living places. Some sent-down youth returned to Shanghai after their retirement. Duo to limited savings and pensions, those sent-down youth could not afford an apartment. Therefore, taking care of senior parents with a possibility of inheriting part or total housing property became the best option. Mrs. Ye (#W22) had a senior brother who was a sent-down youth in Guizhou. She also had an affluent younger brother in Shanghai. When her senior brother retired and decided to return to Shanghai, Mrs. Ye helped him to process his hukou status so that he could stay with their mother.

Since family property was an inevitable issue, I asked Mrs. Ye how she dealt with their mother's housing and eldercare. She frankly said:

> I told my senior brother that he could inherit our mother's housing if he took care of her. Before he returned to Shanghai, my younger brother and I took care of our parents. Now my father has passed away, and my senior brother has to show filial piety to our mother. Moreover, based on our seniority, he is the oldest child in our family. He would have taken my parents' housing if he married then, or the work unit had already allocated him housing. It was the Cultural Revolution that made it so. When I talked to my younger brother, he also felt it was appropriate for him to get the housing. Lastly, he came back from a poor place, and had been suffering most of his life. We should give him some benefits if we can. By the way, we only have a few siblings, so it is easy for us to reach an agreement.

To reach a peaceful agreement needs to balance one's responsibility for eldercare and one's inheritance rights, and to balance benefits of caregivers and their siblings. This process constantly needs to reevaluate one's losses and gains, and one's moral responsibility and legal rights. Mrs. Ye and her younger brother were affluent and consciously aware of their losses if they gave up their inheritance rights. They were happy to do so considering their senior brother's sacrifice for the family and their moral responsibility to help poorer sibling. Thus, it was relatively easy for them to reach a peaceful agreement.

Not all families can peacefully reach an agreement on eldercare and housing inheritance. In some cases, the decision-making process is filled with conflicts, and sometimes it ends up with broken family ties. The case of Mr. Tang (#W28) was not atypical in Shanghai when eldercare is inevitably related to housing property inheritance. Mr. Tang had a senior sister and a younger one. His younger sister got married in Anhui province when she was a sent-down youth there. Unlike other sent-down youth who wanted to return to Shanghai, she decided not to go back because of disagreements on her mother's housing property inheritance. Mr. Tang's senior sister lived in a neighborhood of Shanghai. For similar reasons, she stopped contacting Mr. Tang after their conflicts. These conflicts were all about the allocation of their mother's housing relocation compensation. "According to the law," Mr. Tang said, "the housing belonged to our mother. My two sisters both married and removed their hukou from the household. When I got married, the hukou of my nuclear family were all registered there." Based on the relocation policy at that time, only those having a registered hukou had the right to get compensation. However, the two sisters had a different narrative: each child should get one third of the housing compensation because the housing belonged to their mother. Mr. Tang's mother at that time (around 2006) had already been diagnosed with dementia. Without his mother's clear statement, Mr. Tang had to negotiate with his two sisters. Mr. Tang argued with them, "If you [the sisters] want one third of the compensation, then you [the sisters] have to take care of our mother accordingly, rather than I myself take all care responsibilities." The two sisters eventually gave up the compensation. As a result, they stopped contacting Mr. Tang. The estrangement eventually led to a broken family tie. Mr. Tang said, "When my son got married in 2010, I called them but neither of them answered my calls. I did not know where my younger sister lived, but I knew my senior sister's address. I came to her house, her neighbors told me that she had already moved out. I do not know where she is." The broken family ties further disappointed Mr. Tang when their mother died in 2015. When Mr. Tang called them again, neither attended their mother's funeral.

Those sent-down youth who returned to Shanghai often intensify sibling relationships when there are disputes about housing property inheritance. Mr. Gan (#082) ended up with broken ties with his brother. Like many sent-down youth, Mr. Gan had to transfer his hukou from Gansu province to his original home when he returned to Shanghai. Often, local governments will recommend they register their hukou in their parents' house. This means that these sent-down youth have legal rights to inherit the housing property. In order to hold the entitlement alone, his brother did not allow Mr. Gan to register his hukou in their mother's house. In order to solve their disputes, they met in the police station. According to Mr. Gan, his hukou together with his nuclear families' were eventually registered in his brother's housing, which was a smaller housing than their mother's. This kind of hukou registration also gave him no right to inherit their mother's property. In order to register their hukou, his brother further requested that Mr. Gan had to take care of their mother. The tragedy of Mr. Gan did not end here. Shortly after Mr. Gan registered their hukou, his brother's housing was relocated. According to the relocation policy, those having their hukou registered in the household should be compensated. According to this policy, Mr. Gan and his nuclear family should have been entitled to half of the compensation. However, they got only a quarter because his brother did not allow him to get more. These conflicts had completely undermined Mr. Gan's trust of families. As a result, he developed severe depression. In our conversation, he expressed his ambivalent feelings toward families:

> Previously, I went to the countryside for the sake of my whole family. After I came back, I was estranged by my family. After these disputes, I do not trust siblings or other family. None of them are reliable. Only your parents are yours, and your children are yours.

Negotiated family responsibility, as a more recent social norm based on individual rights of inheritance, was easy to identify during my fieldwork. Family caregivers, especially adult children, were eager to express their moral righteousness or plights during our conversations. Regardless of peaceful agreements or family conflicts, these stories all demonstrated eldercare is inevitably related to the division and inheritance of their parents' housing property. While acknowledging that eldercare based on housing property inheritance is a local norm generated by the public, we should note that those families who end up with broken ties in turn undermine traditional family culture in China. Moreover, those who have received their parents' property often become solo caregivers after their siblings completely resign themselves from eldercare responsibility.

This negotiated care model is influenced by Western individualism, such as the increasing public awareness of individual rights during modernization. However, cases above—especially those with broken family ties—present us with an imbalance between individual rights and corresponding familial responsibility. Rather than emphasizing moral responsibility and the pride of independence, adult children who fight personal benefits without taking one's social responsibility often reveal their selfishness. Adult children who are in disadvantaged circumstances often end up being caregivers, such as those used to be sent-down youth and those left behind in China by overseas siblings. Unlike adult children in individualistic societies who often balance eldercare and individual rights such as work duties by looking for formal care institutions, some adult-child caregivers in urban China regard taking care of elders as a way to negotiate limits upon their responsibility and their personal inheritance rights. Intertwining with traditional filial piety and the public awareness of individual rights, families with dependents such as dementia sufferers are more likely to be associated with conflicts than solidarity, particularly when adult children or their siblings are in disadvantaged circumstances.

Gender Ideologies in Eldercare

A significant body of literature have documented gender differences in selection of caregivers and caregiving activities (Friedemann et al. 2014; Miller and Kaufman 1996; Neufeld and Kushner 2009; Oliker 2011). Contrary to these studies, I argue that a negotiated egalitarian gender ideology in caregiver assignment in Shanghai is emerging. This gender ideology does not necessarily imply egalitarianism in the Chinese society between males and females; rather, it gives us some implications about changing gender roles in family-based eldercare. This negotiated egalitarian gender ideology is evident in the expanding domestic roles of men and the shrinking back of women from traditional gender roles.

Expanding Domestic Roles of Male Caregivers

Within the context of increasing male participants in caregiving, it is not unusual to encounter male caregivers taking care of their spouses or parents. Among the 144 family caregivers, 59 were males (see Table 2). Although rationales for each man participating in caregiving differ, a significant reason is the expanding home-based roles of being husbands or sons. Roles of men have been expanded from being breadwinners to day-to-day caregivers. Correspondingly, home roles of male caregivers have been expanded from the previous tasks that require manual labor to all dimensions of care tasks. These care tasks include shopping for food and personal care items, making medical appointments, communicating with friends or other family members about care recipients' health conditions, providing transportation, managing medications, and even taking personal aspects such as intimate physical care.

The expanding home roles of spousal caregivers are due to the following factors. First, traditional gender roles do not prevent men from becoming caregivers because of the shortage of female caregivers. Among the 144 care recipients, 29 cases (21.1%) were without daughters (they had only one son or sons). When families having daughters (19.4%), they were the only child due to the One-Child policy. Because of their work duties, young females often resigned themselves from traditional gender roles, as I will discuss in the later section (Table 5). This means that female caregivers will become even more insufficient in the future. Mr. Wang (#023) was an ideal case to illustrate this condition. He was officially retired on July 1^{st} 2007. Unfortunately, he became a caregiver three weeks later because his wife fell and broke her hip. After a surgery, Mrs. Wang developed some symptoms of dementia and was diagnosed with dementia in 2010. In order to receive better care, Mr. Wang even took his wife to Chicago where their two sons worked. However, Mrs. Wang's dementia conditions worsened, regardless of the treatments. Due to the deterioration of his wife's health condition, he took on almost all care tasks, including household chores, medical care, and personal care. Mr. Wang expressed this of his unexpected retirement life during the past ten years: "I thought we could travel for sightseeing worldwide after our retirement. I never thought of being a caregiver. Yet, this is our life. She needs me and my two sons are overseas. I have to do my best." Because of limited female family members, some husband caregivers have to shoulder personal care tasks that are traditionally women's roles. Another Mr. Wang (#069) had to take on personal care for his wife because their only son was diagnosed with depression. Instead of outsourcing to home aides, Mr. Wang took personal care and other tasks as his "work":

> I do not feel tired of taking care of her. I treat her as my child. Since she only knows me, I guide her to the bathroom, and bathe her. It's not due to modesty for my [only] son not to do these tasks. They are my work.

Second, there is a flexible gender role for males in domestic settings after several decades of egalitarian education between males and females. News outlets have reported the expanding gender roles of men in their daily lives in Shanghai (Bells 2011; Chen 2012; China Daily 2006). My study also found that some husbands had already engaged in domestic labor before their spouses were diagnosed with dementia. Thus, caregiving was a natural continuation of their previous home roles. For instance, Mr. Feng (#067) took care of his wife who was diagnosed with early stage dementia. When I asked whether dementia affected his wife's cooking skills, he told me that his wife rarely cooked even before her diagnosis. Mr. Feng further explained, "Don't judge me based on our looks. I might look strong and careless, but in reality, I do everything carefully and persistently. She looks tiny and careful, but she often messes things up. So, I do not like her ways of cooking. Since we got married, I have taken most household chores, and she only takes charge of some basic cleaning tasks." Because Mr. Feng had played a dominant role in the domestic setting, he felt it was natural to take care of his wife after her diagnosis.

The expanding of home roles of men does not necessarily reduce their masculinity on the job market. Mr. Shao (#089) was 55 years old. His wife, 53 years old, was recently diagnosed with dementia. Mr. Shao was a famous ping pong coach in Shanghai and often traveled nationwide for competitions and coaching programs. However, when he went back home, Mr. Shao had to give all his earnings and bank accounts to his wife. Additionally, he was in charge of shopping, cooking, and cleaning when he was home. According to Mr. Shao, even after his wife was retired three years ago, he still took care of all household chores except financial management. Previously, he had no idea about how much money they had and how to use bank accounts. Since his wife's diagnosis, Mr. Shao gradually learned how to manage finance. When I asked him whether taking care of his wife was a burden and how he managed his care-work duties, he said, "It's fine for me to take care of her. When I stay home, I cook for her; when I have to travel, she will stay with my son and I will call her as many times as possible." Mr. Shao's ability to manage care-work conflicts had facilitated his exchanges between being a male professional and a family caregiver. The flexible gender roles have blurred the boundaries of work that are traditionally divided based on gender.

Lastly, gender roles continue to dilute at post-retirement stages of life, which makes males getting involved in caregiving possible. Western studies on gender roles have found that distinctions between males and females become less salient along with adult development, particularly at post-retirement stages of life (Gutmann 1980, 1985). Building upon this life-course development theory, some Western scholars further argue that husband caregivers may adjust their gender roles due to the marital contract and the necessity for sustaining the conjugal relationship (Ducharme et al. 2007; Russell 2001). This theory can also explain the increasing number of spousal caregivers in China. Among the 59 male caregivers, 42 were husbands. Instead of pursuing masculinity that might be characterized by carelessness, all husband caregivers demonstrated their "feminine" nature, as evidenced by the above cases. In addition, some husband caregivers transformed their "feminine" caregiving into a sense of masculine achievement. Mr. You (#031) and his wife were in their eighties. He was a business manager before his retirement. After his wife was diagnosed with dementia, he had been in charge of all care tasks, ranging from taking care of her medication to dealing with the intense relationship between their adult children and his wife. When I asked him whether he had struggles with the transition to a caregiver, he laughed and said, "Taking care of family members is in the same vein of taking care of your employees. Now, I just need to take responsibility for my wife, instead of more than three hundred people. I feel proud that her [his wife] memory status does not get worse after six years of diagnosis. I should say that it is closely related to my care." Mr. You's narrative demonstrates his commitment to conjugal responsibility, and the productiveness of his care outcomes, an indication of his masculine nature.

The expanding domestic roles of males are also evident in son caregivers. Among the 59 men caring for a relative with dementia, 17 are sons. Like husband caregivers, son caregivers have to adjust their gender roles to meet care demands. However, the extent of their adjustments differs from case to case. Some solo caregivers who received exclusive property from their parents have to quit jobs to meet care demands. Mr. Fan (#030) quit his job when his parents needed intensive care in hospital. He had to do so because his mother needed emergency care each morning. In order to save time of transportation, he often got up at four or five o'clock in the early morning. Otherwise, there would be a long waiting list in the hospital. When I interviewed him, Mr. Fan had already quit his job for 19 days. Unlike other adult-child caregivers who felt dilemmas about care-work duties, Mr. Fan expressed that he should do so to demonstrate his filial behaviors in front of his siblings since his parents gave their savings and housing property to him. In addition to the medical care, Mr. Fan was in charge of daily necessities of his parents. In order to persuade his parents to eat good food, Mr. Fan often deceived them that all luxury food such as shrimps and fishes were extremely cheap or subsidized by the government. "Otherwise, they would not eat if you tell them the price," said Mr. Fan. Taking care of parents was not the only life purpose of Mr. Fan. When I ask him whether he would go back to the job market, he expressed that he preferred a less time-demanding job to balance work and care demands.

Personal care such as bathing their mothers becomes big challenge for son caregiver if they cannot make adjustment. Due to modesty, Mr. Fan could not stand to bathe his mother. He felt "it is [was] uncomfortable to bathe one's mother, an opposite gender parent." Eventually, he had to turn to his wife for help. Mr. Fan was lucky since his wife was willing to bathe her mother-in-law. Without the help of female family members, some son caregivers have to hire home aides to bathe their mothers. Mr. Qiu (#008) was 29 years old and his mother's gradually lost her ability of continence after a surgery. Since Mr. Qiu was not married and had no female family members (he only had a brother in the US), he hired a home aide to bathe his mother every day. He told me that, “It would be awkward [for him] if someday the home aide is absent.”

The unavailability of private bathrooms further complicates son caregivers’ responses to bathing their mothers.[32] Mr. Sun (#024) was divorced several years ago. He had two brothers who were also divorced and one sister who was abroad. The three brothers, including Mr. Sun, were extremely poor, and two of them relied on governmental subsidies. Mr. Sun became the only caregiver for his mother about ten years ago. After ten years of caregiving, he was able to take good care of his mother except bathing her. Because their house did not have access to private bathrooms, Mr. Sun had to use public bathrooms. Mr. Sun said, “I can give my mother a bath in our apartment in summer, but I have to hire a home aide to bathe her in a public bathroom in winter since I cannot go together with her in the same bathroom.”

If house conditions allow, some son caregivers, even with the availability of their wives, have overcome the awkward psychological condition to bathe their mothers. Mr. Tang (#028) had to take all care tasks for his mother, including bathing and toileting since his mother was incontinent. He shared with me how to maintain a clean body for his mother:

> In the morning, I clean her body with a wet towel, and in the evening, I give her a bath. I guide her to the bathroom every two hours during the day, and I use diapers at night. There are no gender differences between mothers and sons. When I was a kid, my mother cleaned for me until I grew up. Now, it’s my turn to take care of her.

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[32] Some traditional houses in Shanghai do not have private bathrooms due to its century history.

While Mr. Tang indeed received a high reputation based on what he had done for his mother, he also had a nickname “*pa laopo*,” meaning “being henpecked.” Mr. Tang was “henpecked” because his wife agreed to let his mother live with them in a tiny apartment, which, from his perspective, “[she] was good enough to be a wife.” Mr. Tang further explained, “We have to compromise to reach a peaceful agreement. When she agreed to let my mother stay with us to facilitate my caregiving, I also stated that I would not let my mother interrupt her life.” The mutual agreement between Mr. Tang and his wife demonstrates the expanding home roles of son caregivers on the one hand, and the resignation of women—especially daughters-in-law—from traditional gender roles (as I will discuss in the following section) on the other.

Like husband caregivers, son caregivers have engaged in various care tasks, from making healthcare appointments to helping with personal care activities. In order to solve the awkward psychological condition for personal care tasks, son caregivers turned to their wives or other paid care workers for help, or directly did by themselves. Unlike most husband caregivers who are more likely to be retired, some son caregivers are still at the working age. Therefore, they have to balance their care responsibilities and work demands. Some son caregivers have to quit or change their jobs to temporary ones with flexible work schedule to meet care demands. Equally worth mentioning is that some son caregivers have no partners to share care tasks, due to the lack of females around in a family, the unwillingness of sharing care tasks, and potential care-work conflicts. Therefore, male caregivers, particularly son caregivers, often encounter more stressful conditions than female counterparts in practice.

Women’s Withdrawal from Traditional Gender Roles

Along with expanding home roles of males is women's withdrawal from traditional gender roles in domestic settings. Women, particularly adult daughters who had received modern education, negotiate their care obligations with their parents. Their primary concerns are work duties and potential intergenerational conflicts. I met Mrs. Cai (#007) outside of the memory clinic in a cold morning. Unlike most family caregivers who often asked me advice for maintaining family-based care, Mrs. Cai was worried about whether she could find a nursing home for her mother. I knew she was in her forties and it would be impossible to quit her job for eldercare. After we talked for a while, I learned that it was not only about her job concerns, but also potential intergenerational conflicts. According to Mrs. Cai, younger generations could not get along with older ones because of different values. Considering potential conflicts, she said, "If we could not deal with family conflicts properly, it would be awkward and none of us can live happily together." Moreover, Mrs. Cai had her parents, and her husband also had two parents. "If they all stay with us, how can we maintain a normal life?" said Mrs. Cai. Thus, Mrs. Cai suggested that it's better for her parents to go to a nursing home so that both generations could enjoy a peaceful and "normal" life.

Unlike traditional women who often have to prioritize family caregiving roles over other social roles such as fulltime workers, women in urban China prefer to their paid work than the unpaid work such as caregiving in domestic settings. When they encounter long-term care work for parents with chronic diseases, women have to deliberate pros and cons of being caregivers. As the case of Mrs. Cai indicated, the availability of eldercare services in the market—nursing homes and paid care— offer alternatives for women to relinquish traditional gender roles as caregivers. Even for women without work duties, some would prefer work to caregiving. Mrs. Niu (#035) was 63 years old and she should have been retired in her age. However, she continued to work outside because "I do [she did] not like caregiving." Mrs. Niu's father was 93 years old, and her father-in-law was 90 years old. She said, "If I don't work, I will have to stay home to take care of them every day, which will drive me crazy [because of their demands]." In addition to her dislike of caregiving, she expressed the productivity of work. She further explained, "People like me at this age often get a high salary, and I feel comfortable when I work. I can control everything I am doing. But caregiving is not something that I can control at home." The conceptualization of the unproductivity of caregiving on the one hand, and the productivity of work on the other, prevented Mrs. Niu from being a caregiver. Instead, she hired two nursing aides to take care of her father, and her husband was in charge of her father-in-law.

Adult daughters also negotiate care obligations with siblings, particularly with their brothers. Their negotiations are overlapped or partly overlapped with their claim to the housing-property inheritance right. With the rising awareness of women's rights and their role in society, the law of women's inheriting rights in parents' property has been implemented and enforced.[33] Women's active negotiations also narrow the gender gap between care obligations and inheriting rights. Mrs. Xu and her three sisters (#055) together took care of their frail parents who suffered from dementia. Mrs. Xu also had a brother who had migrated to Hong Kong. Their parents had two houses: one was in Hong Kong, which would go to their brother; and the other was in Shanghai, which should

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[33] Women's right campaigns began in 1952 in theory, but women's right in inheritance was only recently and gradually carried out in practice.

belong to the four sisters according to the housing-inheritance norm. Without a written document, the brother in Hong Kong intended to get the house in Shanghai as well. Mrs. Xu said they [the sisters] could give their parents' house in Shanghai to their brother if he took care of them in Hong Kong. However, neither her brother nor her sister-in-law wanted to take care of the senior parents because of their increasing care demands. According to Mrs. Xu, "they just want[ed] the house." Realizing the conflicts, Mrs. Xu and her three sisters took turns taking care of their parents, including the daily care schedule and her mother's medications. She said, "I am the leader of our siblings in Shanghai. I have the decision power. I have told my three sisters that we are going to share our parents' housing and my brother has the one in Hong Kong. I have to hold on. Otherwise, you will not know what will happen."

When there are no family conflicts, women's leadership role in domestic settings is also evident in everyday care practices. They have the power to decide care arrangements, such as labor division among siblings, which is closely related to their economic circumstances. For instance, Mrs. Wang (#103), aged 55 and her brother 53, took turns taking care of their parents. The mother was diagnosed with dementia in June 2017. After taking care of her parents for three months in downtown, Mrs. Wang learned that it would be better for her parents to return to their original place—the Chongming Island—to keep their long-term memory. Their home town was at least three hours of drive from the downtown. In order to take care of their parents, Mrs. Wang asked her brother to retire early and live with them in Chongming Island. When I asked how her brother could be so willing to take care of their parents without work, Mrs. Wang told me that her brother worked in her husband's company. After his retirement, Mrs. Wang said, "My husband's company has paid his social security, and he also has my parents' pensions, which is much higher than his salary."

While acknowledging that women have dominant power in their natal and nuclear families, it is rare to see women who are daughters-in-law take care of their parents-in-laws. None of the 144 families had daughters-in-law as primary caregivers, and only two daughters-in-law directly expressed that they assisted their husbands during caregiving. In the same vein, sons-in-law who got involved in caregiving were often secondary caregivers to assist their wives, rather than primary caregivers for their in-laws. The currently uncommon phenomenon of daughters-in-law taking care of in-laws reveals the increasing decision-making power of women who eschew traditional gender roles in relation to their husbands' extended families. Daughters-in-law, like their husbands, have both parents who are in need of care late in life. With the rising power of decision-making in domestic settings, daughters-in-law would rather choose to take care of their own parents, which equally grants them inheriting rights of their parents' property. Therefore, husbands have to take care of their parents, leading to the increasing number of son caregivers.

Ever since the empowerment of women in China in the 1950s, Chinese women's social status has improved significantly. These above cases supplement the existing literature on women studies by examining women's decision-making power in eldercare in domestic settings. These women who were born in the 1950s or early 1960s witnessed the nationwide gender equality campaigns during the Mao era. Compared to older cohorts such as their parents, their chances for equal education and paid work were much higher. My study found that this age cohort of women was subjected to both traditional norms (e.g., filial piety) and modern ideology (e.g., gender equality) in domestic settings. In the reform era, the One-Child policy campaigns and the popularity of Western thoughts, such as individual rights, have reinforced their notion of gender equality. When traditional family-based eldercare encounters the modern ideology such as individual rights for inheriting parents' property, adult-daughter caregivers successfully integrate their obligations with rights in taking care of their parents. If there are no benefits, women would withdraw from their traditional gender roles, such as being subservient to their parents or parents-in-law. Younger women born in the 1970s or later were still at working age when I conducted my research. Compared to senior cohorts who are more likely retired, younger women prefer paid work to domestic labor. When there are care-work conflicts, women who are career-oriented often turn to social services for eldercare, which facilitates their withdrawal from traditional gender roles.

Family Cultures in Urban China

This chapter discusses family politics of dementia care in Shanghai, with a focus on the intergenerational relationships and gender ideologies. Investigating these two dimensions reveals a transformation of family politics, from the previous patriarchal familism to a negotiated egalitarian familism in urban China.

One important characteristic of the egalitarian familism is that conjugal interdependence—which is replacing the intergenerational dependence—has become a dominant feature of family relations in urban China. Unlike previous studies that mainly focus on the changing power of younger generations, this study found that both younger and older generations are subjected to, but have been actively engaged in, the transformation of family structures during the process of modernization. There are macro-, meso-, and micro- levels of factors facilitating this transformation. At the macro level, older generations in Shanghai have accumulated certain wealth during the past four decades of economic reform. The development of social security system also enables senior citizens to be financially independent from their adult children. Moreover, although housing reform in Shanghai has separated senior parents from their adult children, older generations fortunately possess an important property—the housing asset—that younger generations have to enslave themselves years to achieve. Another result of housing reform is that spouses have become the most proximate family members for caregiving by far. At the meso level, there are push-and-pull factors to compel senior generations to seek mutual support and other modes of care in the market. Push factors include the increasing pressure from work and social competition on younger generations, the shortage of family caregivers due to the One-Child policy, and the individualization of rapidly changing society. Pull factors include seniors' acceptance of Western values, e.g., self-reliance and individualism (Shea 2020), and the growth of the eldercare industry, which provides alternative social support for seniors. At the micro-level, the rising awareness of conjugal intimacy late in life, potential intergenerational conflicts, and the agency of adult children, e.g., negotiating family care responsibility with housing-property inheritance, constantly remind seniors to resort to conjugal interdependence rather than relying on adult children.

Women's withdrawal from traditional gender roles and expanding domestic roles of men reveal a gender egalitarianism of domestic division of labor in urban China. Changing gender ideologies have reconfigured eldercare arrangements. Statistically, gender differences are not salient between numbers of husband- and wife- caregivers, and between son- and daughter- caregivers in this study. While acknowledging that the decrease in the gender gap in eldercare does not necessarily imply an egalitarian gender ideology in China, changing gender-based performances of eldercare is suggestive. First, there is a flexible gender ideology in domestic settings in Shanghai. The increasing number of males taking care of their parents or spouses and of females who are bread-winners does not erase or redefine masculinity and femininity in the broader society. Rather, the eldercare context, i.e., fulfilling one's moral and legal responsibility, promotes a flexible gender ideology in Chinese families. With limited family care resources, unavailability of adult children, and the increasing competitiveness of society, each family member has to adjust their gender roles to maintain family functions. Second, egalitarian gender roles in eldercare are achieved mostly through women's aggressive negotiation, rather than men's recognition of women's rights. Women, especially adult daughters, have to negotiate with their parents, their brothers, and even their husbands about their rights to work, property inheritance, and care obligations. Women who were born in the Maoist China and the reform era have experienced dramatic social changes that serve as a different socialization mechanism by which gender-based systems of thoughts and actions occur. Women are believed to be autonomous, and have equal rights of pursuing career development and taking instrumental behaviors. Therefore, relational and nurturing behaviors of women arise not necessarily from their internal convictions, but from their constant negotiations and comparisons between family responsibility and legal rights (e.g., work, inheritance, and even freedom) in order to find the best solution to maximize individual benefits.

The negotiated egalitarian familism has created a new care norm in urban China — "intimacy at a distance" (Rosenmayr and Köckeis 1965) —that both generations favor. This new norm serves as an alternative strategy for both generations to maintain family unity while keeping a physical and social distance for each to seek individual freedom. The "intimacy at a distance" relationship between generations in urban China is similar to that in Western societies yet with different characteristics. In Western societies such as the U.S., two features characterize the intergenerational relationship: the recognition of the other generation as an adult like oneself, and mutual concern for the wellbeing of the other generation (Conner 2000). The physical distance between generations in America is also important, but the distance is more about social space than physical space. The distance between generations in Shanghai, however, is more about a physical space than a social one. Although parent-adult children relationship manifests itself like the Western norm of "intimacy at a distance," traditional Confucian values and limited social support have deeply colored intergenerational relationships in urban China. Due to the poor social services for seniors, some older parents—particularly those who are economically disadvantaged—have to refer to the cultural expectation that endorses adult-child care. Instead of resorting to other modes of care in the market, these seniors are more likely to disclose their worries and concerns to their adult children than their Western counterparts. In other words, Chinese older generations expect to get support from their adult children even despite a physical distance, while their Western counterparts prefer to use formal or institutional care arrangements to support themselves to live independently. Therefore, even though seniors in urban China have been much more independent than previous older cohorts, their degree of independence is still remarkably different on average from Western societies.

The egalitarian familism in Shanghai also demonstrates another care norm— "filial but not obedient"—that is valued by adult children in contemporary China. Two important pillars that support the traditional filial piety are ethical codes and patriarchal family structures. As Chinese families are becoming more egalitarian-oriented, practices of filial piety have been modified into different forms, which are more about an obligation than the power asymmetry between generations (Jacobs and Century 2012; Shea et al. 2020). Correspondingly, the meanings associated with eldercare are changing from the previous filial piety that emphasizes unconditional obedience, emotional affiliation, and moral fulfillment to the Western ideologies of egalitarianism, rationalism, and individualism. Within this context, adult children should be filial but are not necessarily obedient to their parents, implying that they can take on some filial responsibility but might not be able to fulfill parents' expectations. Even though adult children can contribute eldercare when parents are in need of emergency care, long-term care for ill parents that is exclusively based on adult-child care is not a viable option. In this study, adult children—both sons and daughters—cannot fulfill their obligations without sacrificing important domains of their own lives such as employment, personal time, and family life. Differences between unconditional parent-primacy care and negotiated care responsibility are whether adult children could combine the increasing care demands with their career development, or whether adult children would like to sacrifice their careers and personal lives to meet parents' care demand. For adult children who are at working age, the competitive labor environment will not allow them to quit jobs for a long time, even though they can do so temporarily, as some cases indicated. For adult children who have been retired, they also value personal life such as leisure and family activities, and thus, their sacrifice needs to be complemented by inheriting parents' important property. Moreover, when care work becomes more intensive in terms of time and energy, adult children, whether retired or not, are willing to use other modes of care provision available in the market, indicating that their filial behaviors need to be balanced over time.

Chapter 5 Care as Stewardship: Embodied Practices of Family Dementia Caregiving in Shanghai

Case one: On September 13th, 2018, CCTV-13 (a news channel of China Central Television) reported on a seventy-year-old woman, Mrs. Fan, who was taking care of her husband with dementia in Wuhan. The report noted that Mrs. Fan had invented more than ten assistive care devices, for two of which she had been granted patents.[34] One was an alarm monitoring urine and stool—a wetness sensor embedded into diapers. When her husband soiled his diaper, the alarm would ring. Mrs. Fan could clean him as soon as possible. Another tool was a type of large roomy safety mitt secured at the wrists that would allow patients to wiggle their fingers freely inside but not allow them to scratch at or harm themselves.

Case two: In 2009, Mr. Shan, a high school teacher in my research community, suffered a severe stroke at the age of 60. Although he received immediate treatment, he lost the ability to move his left arm and leg. Then he was diagnosed with vascular dementia in 2015. His wife consulted several doctors and heard that regular exercises of the brain could help him improve memory. As Buddhists, since that time the couple has started to recite Buddhist scriptures for memory training.

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[34] Wuhan Evening News. Sep 8, 2018. "A Seventy-Year Old Grandma Taking Care of Her Husband for More than 15 Years, Invented and Modified More than Ten Care Devices." http://www.xinhuanet.com/local/2018-09/08/c_1123397781.htm

The cases above illustrate some of the ways in which family caregivers are actively involved in daily dementia care in urban China. Although each family caregiver responds to care challenges differently, two important dimensions—tending to the body and caring for the mind— are found in each case. Breaking dementia care down into care of the body versus care of the mind is a convenient way to differentiate different forms of care. In practice, the multiplicity of dementia care is vast, particularly after the introduction of person-centered care and quality care by non-state actors in China. Family dementia caregiving includes: administration of pharmaceuticals, alternative medical care, instrumental care, food therapy, body maintenance, memory training, cognitive stimulation, etc. Therefore, care is an unfolding embodied and material process (Mol 2008), which involves not only particular kinds of subjectivities, but also particular actions, instruments, and technologies. So, how does familial dementia care in China work? How is it managed in practice? What kinds of familial care tend to be effective, or to be considered effective, under what circumstances? When a particular form of care is no longer working, how do family caregivers respond as their family members' dementia worsens and their condition deteriorates? In this chapter, I examine different ways family caregivers interact with medicine and technology to negotiate the outcome of dementia care. I argue that although the medicalization of dementia in China and the Chinese state's legislation mandating family responsibility for eldercare has its limitations, in many ways it does give a boost to the agency of family caregivers in their daily care practices. When family caregivers in China rely on medicine and modern technology for dementia care, the combination of these kinds of legitimized care techniques and the associated sociopolitical and socioeconomic contexts surrounding their use play a large role in shaping the values, meanings, and practices of familial dementia care in a manner that is mostly experienced as enhancement of personal agency and caring capacity.

This chapter is divided into four sections. I first examine the theoretical approaches to care to highlight the concept of "care as stewardship" I proposed. Then, I explore rationales of family caregivers' engagement in biomedical and alternative care. I focus on family caregivers' narratives about the good, the bad, and the ambivalent of various medicinal treatments. Third, I investigate various non-pharmaceutical interventions generated by family caregivers. These care interventions include memory training activities, body tinkering skills, safety strategies, food therapy, and information and communication technologies, all adapted along with the progress of dementia. I focus on new frameworks of dementia care arising around domestic care settings in China, such as the application of assistive care devices. Lastly, I analyze how family caregivers' practices inform us about the understanding of care as stewardship in the global context of dementia epidemic.

Theoretical Approaches to Care

Care has been an enduring and contested issue in social science studies. Sociologists categorize care as "domestic" and "institutional" based on settings, and further divide it into "formal" or "informal" in terms of professionalism. Philosophical analysis also challenges and critiques care and some scholars argue that care is "relational" since it is related to a care receiver and a care giver, regardless of its subtypes. Anthropologists also contribute to the debate of care, and some scholars conceptualize care as "labor," concerning the political economical aspects of social life, and care as "kinship" in terms of sociocultural norms. While each approach is significant to enrich our understanding of care, I propose a less common, but equally important approach of care as *stewardship*, which involves a moral marshalling of social resources for the good of a care recipient.

In order to discuss care as stewardship within the context of family dementia caregiving, I will start with a brief discussion about the anthropological approaches that conceptualize “care as labor” and “care as kinship.” Later I will argue that the stewardship approach offers a new perspective to understand care. Both “care as labor” and “care as kinship” approaches have focused on the intersection between gender, ethnicity, affect, mobility, morality, life-course, and political regimes. Care as labor is constructed within the political economy framework; it is closely linked to concerns about decreasing family resources for both child-care and eldercare in developed countries (Colen 1995; Glenn 1992, 2010). Care as kinship is constructed within the sociocultural framework (Aulino 2012; Buch 2015; Faubion 2001). This approach focuses on the sociocultural construction of kinship practice within social networks and relations. Care as kinship practice is often related to intergenerational reciprocity and mutual support within domestic settings (Block 2014; Connolly et al. 2017; Ikels 2004).

Care as Labor: Although forms of “care as labor” vary in different settings, the essence of care is the same: viewing care as a professional and commodity activity to sustain biological and social life over time and across generations. This approach defines care from the perspective of social reproduction that is associated with stratification and inequalities across both time and space (Brijnath 2009; Colen 1995; Degiuli 2007; Ehrenreich and Hochschild 2002; Yeates 2009; Zimmerman et al. 2006). For example, as population aging worldwide, wealthy families in developed countries hire lower status, poorer, and migrant women from developing countries to sustain their lives and ways of living, which creates a global care chain. This chain is also linked to the neoliberal strategies adopted by governments that have retracted public health and welfare programs (Estes and Binney 1989; Lock 2013; Wentzell 2013). The neoliberal politics further compels families to take the moral responsibility of both childcare and eldercare as a way to prioritize economic development. This moral economy—the interplay between cultural norms and economic activities—seems to bring together "care as labor" and "care as kinship"; however, scholars often emphasize the sociopolitical context and various ways in which social pressure coerce economic actors in a society to conform to traditional norms (Chattoo and Ahmad 2008; Näre 2011; Taylor-Gooby et al. 2019).

Care as Kinship: The second approach situates care in the context of the sociocultural construction of kinship. It focuses on the role of care in the reproduction and maintenance of kin. Like other forms of social relations, kinship is shaped and maintained through cultural norms. Therefore, care—being attentive to and tending to the needs of others—is needed to contribute to the making and maintaining of kinship relations. Scholars have examined the intergenerational circulation of care (Block 2014; Livingston 2003, 2005), values attached to care as a kinship practice (Brijnath 2014; Cohen 1998; Kleinman 2009, 2012), and how socioeconomic changes affect this practice (Ikels 2004; Lamb 2009; Traphagan 2000). What these works have in common is that they look at moralities and social norms attached to relations of caregiving. Given this context, care is perceived as both an obligation and a right, and both a burden and an affection. From the life-course perspective, one's obligations to give care and rights to receive care change over time, which significantly affects one's sense of relatedness (Feldman 2017; Kropf and Greene 2014; Häberlein 2015). During the rapid modernization, care associated social norms (i.e., the rights and obligations) are subjected to broader social and political changes, which directly affect an individual's position in domestic settings and meanings attached to care practices (Shea and Zhang 2016; Yan 2016; Zhang 2017a; Zhang 2017b). Therefore, the care as kinship approach is one way to understand the moral norms that arise from the inner convictions of caregivers, and external social values regarding what is expected of a good son, daughter, wife, husband, or other kin (Robbins 2013).

While each approach situates care within a particular structure and system that casts it either as a socioeconomic resource or as an intersubjective moral practice, both neglect the everyday, experiential, and embodied aspects of care. By this I mean how caregivers actually perform care, how caregivers respond to daily care challenges, and how caregivers engage with surrounding resources to negotiate care outcomes. In other words, the performativity of care such as the agency of caregivers and their moral practices are largely overlooked in scholarly care literatures. Family caregivers are worthy of special attention because the illness experiences of patients (especially for those in late-stage dementia) are closely bounded with the experience of family members caring for them. Therefore, the examination of how family caregivers actually practice the day-to-day care not only brings together the two approaches—care as labor and care as kinship, but also enriches our understanding of care as stewardship.

Stewardship can be viewed as an ethically informed or “good” form of governance or management in many fields, such as religion, ecology and public administration (Saltman and Ferroussier-Davis 2000). This term is traditionally defined as a theological concept that humans are responsible for the world and should take care of it. Subsequently, the environmentalism movement emphasizes present generations’ stewardship of our natural resources for future generations (Bennett et al. 2018). The theory of stewardship has also been applied in governance studies of social organizations (Armstrong 1997; Kass 1990), and studies of the nursing leadership, which involves integration across provider settings and new models of care delivery (Dingel-Stewart and LaCoste 2004; Murphy 2009).

The theories of stewardship largely derive from studies of agency. Some scholars, such as Mol and colleagues (2010), analyze care by emphasizing caregivers’ agency in terms of the interaction with knowledge, material, resources, tools, and techniques. Their studies of care in practice are based on the notion of the “techniques of the body” (Mauss 1973), the Levi-Straussian bricolage (Levi-Strauss 1966/1962), and Sennett’s (2008) work on everyday craftsmanship. The concept of distributed agency (Gell 1998; Kohn 2013) is also relevant to this study in terms of bridging the gap between “free will” kind of extreme individual agency and being controlled in a Foucauldian way by hegemonic governmental, institutional, scientific, and medical structures.

Building upon agency theory (Kiser 1999; Shapiro 2005; Weber 1924/1978) and ethical studies of care (Barnes 2012; Brannelly 2006; Tronto 1993), I argue that stewardship approach offers a new perspective to understand care. I use stewardship to draw attention to the transformed social contexts of dementia care by medicine and modern technology and its practices that can achieve morally preferable health outcomes according to family caregivers. This project takes elements of both the care as labor and the care as kinship approaches to frame care as stewardship within particular situations. That is, I focus on family dementia caregivers' subjectivities and practices and their interactions with surrounding knowledge and techniques and how they use them to negotiate structural and systematic care constraints. These techniques encompass recourse to high technologies for assistance, everyday technologies for living, and home-made care devices for convenience. Crucial to the understanding of stewardship in dementia care is the agency of family caregivers and the diverse forms of moral reasoning underlying heterogeneous practices of caregiving. The following sections will focus on the embodied care practices as stewardship by family dementia caregivers.

Rationales of Family Caregivers' Engagement in Biomedical and Alternative Care

During my fieldwork, family caregivers were very active to engage in biomedical care. Among the 144 care recipients, only five had not received or rejected treatment due to various reasons (see Chapter 6). Family caregivers who engaged in medical strategies aimed to achieve better care outcomes, and some even tried to combine biomedicine with alternative care. These caregivers constantly consulted physicians regarding their kin's dementia, consulting biomedical doctors across the board and in some cases also consulting traditional Chinese medicine doctors. Their main question was whether there were effective medications that could treat or reverse dementia. While there is as of yet no effective treatment or cure for dementia, medications and therapies are available to manage symptoms and slow disease progression. In memory clinics, doctors explained to family caregivers that medications and therapies were to slow down dementia and/or to ameliorate some symptoms. For those family caregivers who sought alternative care to supplement biomedical treatment, they utilized herbal medicine and/or acupuncture to ameliorate dementia symptoms. Most family caregivers said that they were aware of the limited effectiveness of various treatments, but they also expressed concerns about failing to try medical interventions. They gave three reasons for actively engaging biomedical and alternative care for dementia patients: hope for clinical improvement; maintenance of "quality of life"; and the moral obligation to "preserve life through medicine."

Hope for effective clinical care

The family caregivers interviewed for this dissertation expressed high hopes for medical treatment and were very active in this process, often taking initiative in a variety of ways, rather than being merely reactive and compliant to a doctor's instructions. Once a diagnosis of a certain type of dementia has been made, physicians discuss in detail with patients and their relatives what treatment will entail. Unlike with cancer in China or with dementia in South Korea (Lee 2019), most patients in China—especially in the early stages of dementia—will be told about their diagnosis in Shanghai. The information is to get both patients and their families actively involved in both medical and non-pharmaceutical care. There were also patients and families interviewed in Shanghai who denied the diagnosis and sought various physicians for a different opinion. But, eventually, both patients and families accepted the diagnosis and sought medical treatment. Regardless of acknowledging the diagnosis or not, both patients and family caregivers stretch themselves to seek biomedical solutions for dementia, including attending lectures, participating in trial medicine research, seeking the best physicians, and even taking out-of-pocket medications.

Mrs. Xu's case illustrates how family caregivers in Shanghai actively engaged in biomedical treatment through communicating with medical experts, searching online, and mobilizing their social and financial resources to find the best drugs on the market. Mrs. Xu's (#047) husband was diagnosed with dementia in 2005 when there were no drugs available for dementia treatment in China. After consulting many doctors, Mrs. Xu learned that there was a drug—Aricept—in Japan. Originally, she thought to go to Japan to buy this drug. But she found a drugstore that could help to import it if she paid up front. From 2006 to 2007, she gave her husband imported Aricept from the drugstore. It was not until 2008 that Aricept was available in hospitals in Shanghai. But at that time, Aricept was an out-of-pocket drug. It was not until 2013 that this drug was covered by health insurance. Mrs. Xu said, "I don't care how much money I spend. My hope is for my husband to get the best treatment no matter how much it costs." Mrs. Xu actively searched online about progress in dementia treatment. She recently learned about Oxiracetam injection, which was out-of-pocket and cost about 700 RMB ($98 USD) per day. "Hey, if it's effective, I'd pay 7000 RMB ($980 USD) for it," said Mrs. Xu.

In addition to seeking biomedical treatment, some family caregivers actively educated themselves about the science of the disease and transformed themselves from lay persons to what is referred to in China as "half-doctors." Mr. Zhou (#006) started to attend lectures, seminars, and workshops related to dementia after his wife got a diagnosis. Since Mrs. Zhou was in her early stage of dementia, this couple often went together to attend lectures given by professionals from the Chinese Academy of Sciences, the renowned Zhongshan Hospital, and the Citizen Lecture Hall (a municipal organization hosting regular lectures given by prestigious professors at universities in Shanghai).

Moreover, Mr. Zhou bought many dementia textbooks to study its causes, treatments, and prevention. After several months I met this couple again, Mr. Zhou could give a cohesive explanation about causes of dementia and potential treatments. He even asked me about the vaccine in development for preventing Alzheimer's disease. He said, "The XXX research team are working on this vaccine, but they do not say that it works yet. They are still in the pilot stage. I hope more significant progress can be made in dementia study."

Because of ineffective treatment, many patients or their family caregivers actively join research teams as human subjects, and family caregivers are also active shoppers for the best trails.[35] Some studies involve little to no risk of harm as solid safety testing has already been completed, but other studies involve testing drugs in early trail phases when safety is not yet firmly established. Mrs. Sun's (#W04) husband was diagnosed with dementia about ten years ago (around 2007) when there were no effective drugs available in Shanghai for symptoms or slowing the disease. Originally, her husband took a trial drug made by Fudan University. They said that he took the medication with the hope of "*si ma dang huo ma yi*," that is, both treating a dead horse as if it were alive in the hopes that it will get well and live. But later when she heard from another family caregiver in the community that new drugs were available in another hospital (which had already gone from trial to treatment), she had her husband swap to that treatment. She said her decision to change trials, "I am always hoping that he can receive the best care."

In order to get the "best" outcome of biomedical treatment, some families try every method to search for medical options beyond the advice of a single diagnosing physician

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[35] Family caregivers shared a lot about the availability of drugs or their clinical phases either online or offline. In my research clinic, there was a physician directly in charge of the pilot treatment. Some early stage patients actively got involved in the research.

or team. Mrs. Pan's (#011) mother was diagnosed with dementia in a local hospital in east Shanghai. But, she wanted another opinion from the "best" doctors. She used the app "Good Doctors" to search who was the best doctor on dementia treatment. She said, "I believe in scientific treatment for dementia. No matter how far away, I will try to find the best doctor as long as I can afford it." Her efforts were effective since Dr. Y in the memory clinic where I did my research, gave her a second opinion that her mother could be a "fake dementia patient" due to her long term depression whose symptoms could appear as dementia. Mrs. Pan told me, "Real dementia is Alzheimer's disease, which is a world-wide conundrum. President Reagan and President Thatcher got this disease and even they were not able to get effective treatment. I am worried about my mother's condition, and that's why I want her to see the best doctor."

Compared to Ikel's research in 1998 when most Chinese citizens believed that dementia was a sign of normal aging, the public now consider it as a disease condition. Coupled with the medicalization of dementia is the normalization of biomedical treatment for this illness. Biomedical care has become a standardized strategy to try to improve dementia patients' conditions, particularly for those in the early stage. Family caregivers believe that, if dementia is a disease, it can and should be addressed by biomedical treatment. Even though effective drugs able to stop or reverse the progression of dementia are not available on the market, family caregivers pay close attention to the progress of biomedical solutions, such as vaccines for prevention and studies on dementia treatment. Equally important is the access to the most recent research outcome of dementia. Family caregivers use the Internet as a way to gain information related to dementia, such as disease symptoms, treatments, and even the "best" doctors. The development of information technology in China such as various apps (e.g., the Good Doctor, MicroClinics, etc.) also overcomes structural disparities to help average families gain access to the most prestigious physicians.

The maintenance of "quality of life"

Although the definition of quality of life varies according to each family caregiver, the ability to manage one's daily life and physical and mental health are highlighted by all families. Families expressed that the diagnosis of dementia was the beginning of some deterioration in life quality. However, even though some abilities that family caregivers consider important were gradually lost as the disease progressed, caregivers felt that quality of life could be maintained well into the disease process through active biomedical treatment.

Mrs. Li is an active person who has financially invested a lot on her husband's health conditions. Mrs. Li's (#W35) husband was identified to have brain atrophy through physical examination of MRI. Mrs. Li was worried about further decline into dementia. So she consulted several doctors and found a medicine—Oxiracetam—that was claimed to be able to prevent and treat early-stage dementia. Even though this medicine is expensive, Mrs. Li was willing to spend money to take care of her husband's brain. She said, "Now we have to spend a lot of money to maintain our health. We spend one third of our pensions on healthcare each year. If not, our health conditions would get worse. Dementia deserves special attention. I have seen many dementia patients who cannot find home and cannot recognize people. Their lives are too pitiful. Some people claim memory decline is normal, but you really hurt yourself if you don't seek treatment."

Biomedical treatment is not only to maintain patients' abilities of daily living, but also to reduce family care burdens. As the disease progresses, what matters most for caregivers is not only the forgetfulness of patients, but also changes related to increasing care burden. These changes, including getting lost and difficulties in eating, dressing, and toileting threaten the life quality of patients and increase care burden on family caregivers. Accordingly, the biomedical treatment is at least twofold, for the sake of patients to maintain the abilities of daily living, and to reduce care burden on their families. Mrs. Mu's (#005) mother was diagnosed with dementia three years ago. She was eager to have more effective biomedical treatments since she noticed that her mother was no longer in early stage. She said, "I did not expect biomedicines can reverse the disease, but I do hope there is a drug that can help her maintain some abilities of daily living. If she could eat and go to toilet by herself, then that will reduce our care burden." Most family caregivers prioritize biomedical treatment when patients are in the early stage due to the hope of maintaining some functioning in the person with dementia. Mrs. Jiang's (#042) husband originally did not want to see doctors even though he realized that his memory became poor. But, Mrs. Jiang persuaded him to see doctors: "You are now in early stage. The disease will progress if you do not get treatment. If your reluctant to get treatment leads you to become unable to recognize families and to take care of yourself, then, how can you be considered a person with responsibility for his duty toward the family?! Do you think that life is worthwhile or worthy in that condition?" Eventually, spurred by the moral pressure to be responsible to others, Mr. Jiang took his wife's advice to seek biomedical treatment.

Another aspect to understand the bonding nature of the quality of life between patients and their caregivers is the failure of normalizing (some types of) dementia as a chronic disease. While the onset of dementia cannot immediately remove a patient's cognitive abilities, the deterioration of the illness will outbreak at any time. The "unpredictability" of dementia prevents itself from being a stable, chronic illness. Dementia symptoms, e.g., being suspicious or agitated for no reason, and sleep disturbances, are common reasons that are directly associated with quicken progression and an increase in care burden. When caregivers feel that the burden is beyond their capacities, they often turn to biomedical care for solutions.[36] Mr. Gan's (#082) mother was a hundred years old and had a type of dementia that made her extremely agitated, sleepless, and delusions at night. Mr. Gan originally did not want to give any medications to his mother because she was too old. Eventually, Mr. Gan could not take care of her since she did not sleep all night. Mr. Gan said, "If she didn't sleep, I didn't sleep. How can I continue to take care of her during the day? I realized that I have to give her some medicines so that I can sleep well."

Even though family caregivers believe that biomedical treatment is one way to improve dementia conditions, they maintain a critical attitude toward psychotic medications. Seeking psychiatric treatment often has to be done only when patients' symptoms are out of control.[37] Previously, psychiatrists were the primary physicians for dementia patients, especially for those with aggressive symptoms. Given the context that mental diseases are

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[36] Traditional Chinese medicine is often suitable for people with early stage dementia. This is not only because patients can consciously obey physicians' instructions, but also due to its potential clinical effects. Yet, patients with psychiatric symptoms are often suggested to biomedical care in Shanghai.

[37] In China, mental health care and general health care are structurally two different systems. Since mental disorders are severely stigmatized in China, most patients and their families would like to actively engage in biomedical treatment such as neurology, gerontology, and memory clinics.

severely stigmatized in China, most family caregivers and patients cannot accept the diagnosis of dementia as a mental disorder and they would rather turn to neurologists for treatment.[38] Some caregivers even doubt that the benefits outweigh the costs of antipsychotic drugs to treat dementia symptoms, since most antipsychotics are sedatives with potential severe side effects. In dealing with psychiatric symptoms, caregivers have to constantly balance the pros and cons of these sedatives when their family members' conditions get worse. After years of caregiving, some family caregivers have accumulated a lot of experiences on the use of antipsychotic treatment. Mr. Shao (#W36), taking care of his mother for more than ten years, told me about his mother's experience of taking sedative drugs, e.g., Olanzapine:

> To make sure that her illness does not get worse, I do not give her Olanzapine if she can sleep well at night. If I give her Olanzapine, she would sleep all day and night. I have consulted a gerontologist who also recommends that I do not give her Olanzapine too often. It is better to let her brain be "excited" so that it will not decline too fast. The disease comes from her brain, and if I continue to give her sedative drugs, the brain atrophy will deteriorate too fast.

Trying to maintain a good quality of life for dementia sufferers at home represents both an important goal and a difficult challenge for family caregivers. Factors influencing quality of life of people with dementia include patient's functional and cognitive capacities, perception of potential care burden, and the pros and cons of antipsychotic

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[38] Patients will turn to psychiatrists with aggression, such as hurting others or self-hurt. Other conditions, such as sleeplessness, agitation or delusion will be generally treated by neurologists or other professionals in general hospitals. More details can be found in Chapter 1.

drugs. Many caregivers believe that certain biomedical treatments are crucial to improve patients' life quality, but, simultaneously, they reject or try to minimize the use of antipsychotic drugs. While the medicalization of dementia seems to have placed patients and their families into a passive position of receiving medical care, family caregivers are also highly active agents on behalf of their family members and themselves. Pursuing of medical care is at least in large part for family caregivers an experience of maximizing individual agency to negotiate the best health outcome of patients.

The moral obligation to preserve life

Even though dementia sufferers are considered to have poor life prospects and diminished abilities as disease progresses, family caregivers still have a moral obligation to take all necessary means to preserve as much as possible the cognitive abilities of their kin with dementia. Both biomedicine and alternative care, e.g., acupuncture and herbal medicine, offer options for family caregivers to negotiate moral status and health outcomes.

Rationales for family caregivers engaging in biomedical treatment vary according to their moral reasoning. Such moral reasoning often becomes critical when the caregiver knows that there is no chance of making a difference in cognitive function. Mrs. Hao's (#004) mother had moderate dementia. After years' treatment, she noticed that her mother's condition was getting worse and worse. People around told her to "let her go," but Mrs. Hao insisted on taking her mother to memory clinics for treatment. She said, "I do not have any hope that the treatment will be effective. The reason I take her to doctors is that I will not have regrets that I haven't done enough when she dies. It makes me feel better if she receives biomedicine." Mrs. Xi (#041) held a positive attitude to biomedicine after she witnessed her two neighbors died of dementia without any treatment, whereas her in-laws who had taken biomedicine were still alive and reasonably well. The reason for her in-laws to have biomedical treatment was the family's moral obligation of giving them a little bit of enjoyment in their final years, considering that they were in their eighties and had difficult lives. Mrs. Xi said, "They had eaten too much bitterness in suffering to take care of us when they were young. Now they are old and have dementia. They have had few opportunities to enjoy life. We want our parents to be treated with biomedicine so that they can live longer and at least enjoy some good food." Another caregiver, Mrs. Hong (#017), felt that she had the moral responsibility to take her husband for biomedical treatment because he had his own pension. Even after her two sons expressed sentiments that the treatment was useless, Mrs. Hong insisted that she wanted to have a try as long as there were options. Recently she had heard about an additional two medications, and she consulted doctors to see whether her husband could try a new treatment plan. She told me that, "I know this disease cannot be treated. But since my husband has his pension money and health insurance and it will not cost us too much money to treat his illness, I should take him for treatment and try whatever methods there are to see if we can get anywhere with it."

When biomedicine is not as effective as expected, some caregivers feel that they have a moral responsibility to try alternative medicines, most notably traditional Chinese medicine. Since Chinese medicine is also covered by healthcare insurance in China, these caregivers do not hesitate to have a try as long as it does not harm patients. Mrs. Zheng's husband was diagnosed with Alzheimer's disease at an age of 52. She was unprepared for the pain and anxiety related to such a diagnosis. After they consulted several prestigious medical professionals, Mrs. Zheng realized that no drugs were available to reverse this disease. So, she turned to traditional Chinese medicine—both herbal medicine and acupuncture—for help. The good news was that there was a famous physician who specialized in acupuncture therapy of Alzheimer's disease. Since her husband was in an early stage, acupuncture therapy was feasible. After one month's treatment, Mrs. Zheng told me that, "Previously, my husband often felt confused from the hospital to his work unit. Now he can go back and forth by himself."[39] After witnessing her husband's health improvement, she further tried to see whether herbal medicine treatment was effective. "As long as we have options, I want to have a try so that I will not have regrets," said Mrs. Zheng.

Considering family caregivers' eagerness to seek treatment, physicians in the clinic I researched also encourage them to try traditional Chinese medicine if they believe in it and if their economic conditions allowed them to do so. Many caregivers consider biomedical doctors' openness to various treatments as a high moral responsibility. Mr. Zhou's (#053) mother was diagnosed with dementia six years ago. He had a good impression of Dr. Y because he recommended the integration of biomedicine and traditional Chinese medicine for treatment. Since there are only five tertiary hospitals in Shanghai specialized in traditional Chinese medicine and all of them had their clinic and expert information online, it is relatively easy for family caregivers to identify a Chinese medicine doctor specializing in dementia care. Another important source for finding traditional Chinese medicine practitioners is from other patients' effective treatment

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[39] Mr. Zheng, the patient, was still working in a state-owned company when I conducted my fieldwork. His conditions maintained well due to the early stage of the illness and the combination of various treatments.

experiences. Family caregivers often exchange treatment experiences both in and out of the memory clinic, whether in clinic registration lines or the waiting room or outside in person or online. Recently, Mrs. Zheng (#070) heard from another family caregiver that they often visited a traditional Chinese medicine doctor in Beijing. The patient's health conditions had been maintained very well over the course of several years' treatment. Mrs. Zheng wanted her mother to have a try at slowing down the progress of the diseases. Siblings of Mrs. Zheng who were abroad also encouraged her to take their mother to have a try, no matter how much money it cost.

Family caregivers felt that the most reliable way of supporting health and maintaining quality of life was through the biomedical treatment and various alternative care, since they represented the highest form of scientific knowledge and technology. A good family caregiver is morally obligated to take care of a patient's health from the point of diagnosis to the end of patient's life. For most caregivers, they hope to prolong the lives of their kin and if possible preserve some of their cognitive abilities in so far as it is in accordance with the natural end of life. Of course, there are many paths for pursuing health, functioning, and quality of life, and there are also many ways to negotiate the journey of being a morally solid caregiver. The following sections discuss the non-pharmaceutical care generated by family caregivers during their daily life experiences.

Non-Pharmaceutical Strategies and Everyday Techniques for "Good" Care

In Western societies, non-pharmaceutical strategies for dementia care include reality orientation, reminiscence therapy, validation therapy, multisensory therapy, cognitive stimulation therapy, music therapy, environmental manipulation, and behavioral management techniques (James and Fossy 2013). These strategies have been widely adopted by professional caregivers and family caregivers. Recently, non-state actors have introduced these interventions to urban China and have disseminated them through public media (e.g., TV, App, newspaper, radio, etc.), as well as online and offline training and information sharing (see Chapter 2). When I conducted my research in Shanghai, various dementia-care stakeholders had already gained a sense of non-pharmacological care and had adopted various strategies in eldercare facilities.

Family caregivers adopt various non-pharmaceutical strategies in everyday care practices in Shanghai. Yet, unlike the aforementioned “professional” non-pharmaceutical care, they creatively adapt everyday tech to fit a variety of needs of patients. These strategies include: everyday techniques to boost brain functions; tending to the body using high and low technologies; kitchen and toileting technologies to ensure nutrition and cleanliness; tracking devices to balance freedom and safety; and information and communication technologies to connect with the world. While most technologies are not devised with an elder user or a dementia sufferer in mind, many family caregivers are creatively appropriating a wide range of materials and technologies to achieve specific goals. In this section, I focus on the everyday technologies and techniques adopted/generated by family caregivers to maintain and balance the multiple, simultaneous streams of care practices. I also address how these caregivers achieve “good” care and make meaning of their practices. My focus on the everyday tech and meaning-making in family caregiving for dementia patients will transcend the boundaries between body and mind, health and illness, high and low tech, as well as formal and informal care.

Everyday techniques to boost brain function

Cognitive training is a central to helping patients to maintain function. The spectrum of everyday techniques that foster cognitive functions in dementia sufferers is broad, including everything from word/color/number games, to reciting poems, doing calligraphy, playing chess, keeping a journal, and playing music instruments. Some people with dementia prefer to stay home and do these activities by themselves, and others like to join a group of people to practice. Regardless of the formats, family caregivers creatively utilize their daily activities to help boost brain functions.

Several couples mentioned the importance of everyday instruments—such as brushes, chess, cards, Mahjong tiles, newspapers, televisions, pianos, computers, etc.—to help patients to engage in activities that can improve both their memory and mood. These varied depending on the dementia sufferers' preferences and abilities. Mr. Liu (#031) applied various techniques to boost his wife's memory capacity. After breakfast, this couple stayed home to write a Tang poem in calligraphy using brush and ink. After writing out the characters comprising the poem on a large sheet of paper several times, the couple recited the poem together. Since his wife had poor memory, they only wrote and recited one poem each week. After writing and reciting, they also exchanged their understandings about the meaning of poem. In the afternoon, this couple played various games, including Go, chess, and cards, and sometimes they would join their friends to play Mahjong. Mr. Yu (#057) used the computer to help his wife maintain her cognitive abilities. Although Mrs. Yu had lost quite a bit of her language abilities, her calculation abilities were well preserved. Mrs. Yu had no hobbies except playing stocks. After Mrs. Yu was diagnosed with dementia, her husband took over the main finances of the household but gave her a small bank account with fifty thousand RMB to play stocks online. Mr. Yu told me that, “With the online stock training, she can remember these different stock numbers that I could not even understand.”

Family caregivers have to figure out exercise opportunities if their families do not have hobbies or have no interest in continuing their previous hobbies. For example, Mrs. Li (#003) asked her husband with moderate dementia to separate red beans from green beans into two different bowls. This exercise not only helped her to prepare each type of beans for food but also preserved her husband’s balance abilities and the capacity to identify colors. Mr. Gong (#058), who took care of his wife with an early stage of dementia, asked his wife to join him in the daily activity of food shopping. On the way to the food market, Mr. Gong told his wife what kinds of vegetables to buy. When they arrived at the market, he would let his wife find the vegetables. Sometimes Mrs. Gong could find them, but often she failed. On the way back home, Mr. Gong asked his wife the name, the price, and the amount of each vegetable they bought. When they went back home, Mr. Gong asked his wife to write a journal of the food they bought and calculate the money they spent on food every day. Mr. Gong said, “She has relied on me for her whole life, but now she has to learn to be independent.”

Cognitive training can serve a variety of purposes. In Zhen’s family (#071), Mrs. Zhen asked her husband with moderate dementia to write a memo for her about the activities they scheduled and appointments they made with others. The size of the memo was very large with dates on each page. Mr. Zhen had to find the correct page each time, which trained his time orientation. Since Mrs. Zhen had glaucoma, when she needed eye drops, she often asked her husband to find the drops bottle for her to practice his space orientation. Mrs. Zhen also “trained” her husband to manage his morning, noon, and evening medications by putting them into different color boxes. For example, after breakfast, Mrs. Zhen asked her husband what time it was, and which box of medicines he needed to take. In this way, Mrs. Zhen helped her husband exercise his cognitive and organization abilities. In Chen's family (#012), Mrs. Chen used the test of "100 minus 7" (a test included in the mini-mental state examination, MMSE) to make sure that her husband maintained the calculation ability. This test was very popular among family caregivers since it is easy to do, and doctors usually ask patients to do this test in memory clinics. In addition to the "100 minus 7" test, Mrs. Chen asked her husband to recite families' phone numbers, including her own and their daughters'. Mrs. Chen said he could be able to remember these phone numbers if he got lost.

Some family caregivers use religious practices as a way of memory training. Mrs. Xu (#084) usually recited Buddhist scriptures with her mother after breakfast. After reciting, Mrs. Xu would ask her mother to write down scripture and sing Buddhist songs. Mrs. Xu told me, "My mother originally organized her daily activities in this way before she got dementia. So I just keep this routine to make sure she maintains the rest memory." Mr. Zhang (#106) and his mother were also Buddhists. Mr. Zhang asked her mother to check the calendar every day since they needed to burn incense and pray on the first day and the fifteenth day of each lunar month. When Mr. Zhang returned home from work, he accompanied his mother to recite Amitabha with the prayer beads. The Ding (#072) couple applied Bible study as a way of cognitive training. Mr. Ding, a Christian for more than twenty years, was diagnosed with early stage dementia in 2017. He and his wife kept up their habit of reading five chapters of the Bible every day and praying before meals. Mr. Ding told me, "We live with faith."

These above daily exercises might be summed up as “preventive medicine” or “intervention medicine” using a biomedical model. However, regardless of whether these activities could bring biomedical effects, I argue that they are strategies for family caregivers to negotiate the boundary between health and illness. These daily care routines are extensions of lifelong mutual support between spouses and between generations. Therefore, they have less to do with a medical model, and much more to do with lifelong patterns of support. Combining everyday techniques, instruments, and activities eventually promotes wellbeing, comfort, and confidence.

Instruments or exercise techniques can also be seen as accessories to caregiving and memory training, as they not only enable care recipients and caregivers to stay together, but also provide opportunities for family caregivers to coordinate care practices and other daily work. In sum, the various techniques that family caregivers utilize go beyond the expected to include a list of instruments that can boost dementia sufferers’ cognitive abilities and enhance wellbeing and confidence. The following sections continue the exploration of the everyday techniques that family caregivers adopted in care practices.

Tending to the body: from high-tech to home-made care devices

Most family caregivers rely on assistive care devices to improve patients’ quality of life and to facilitate caregiving. Some devices are high-tech such as ventilators, home-oxygen equipment, and adjustable beds. Clearly, not all families can afford high-tech devices. Other family caregivers utilize everyday technologies such as wheelchairs, senior toilet seats, air mattresses, blood pressure monitors, etc. There are also family caregivers who are skillful craftsmen and generate special devices by themselves, as in the first scenario I presented in the beginning of this chapter. So far, few scholars have explored how family caregivers actively apply these technologies as tools to facilitate caregiving and self-care. I am arguing that the application of various technologies during caregiving further blurred the boundaries between formal and informal caregiving, and between institutional and domestic care.

For family caregivers with whom I spoke, the high-tech care devices hold instrumental and symbolic meanings associated with mortality, care coordination, and the quality of life of dementia sufferers. After Mr. Li (#051) broke his ribs in a fall, her daughter, Mrs. Li, bought a 20,000 RMB ($2800 USD) ventilator for her father to facilitate his breathing. She learned how to use the ventilator at home after consulting with several doctors and nurses. She told me, her father would cry from chest pain when he coughed. His pain further affected his breathing, which made his dementia condition worse. The serious result was delusion. If Mr. Li's breath improved, his recovery was quicker. Mrs. Li explained, "The ventilator is probably the most important thing for my father because it means life and death." Since dementia can be caused by ischemia and hypoxia, some family caregivers buy home-oxygen equipment for their kin with dementia. Compared to the ventilator, home-oxygen equipment is much cheaper (about 4000 RMB, $560 USD) and many families can afford. Mr. Huang (#015) bought an oxygen machine for his wife due to her low blood pressure, which was low enough (50/70 mm Hg) to threaten her life. Mrs. Huang carried the oxygen equipment wherever she went.

Mr. Shao (#W36) constructed a "special care unit" for his mother, who had dementia and Parkinson's disease. He adopted a list of devices to facilitate care, including an oxygen machine, an air mattress, different types of walkers, a medical adjustable bed, a blood pressure monitor, and a senior toilet seat, each with a particular purpose. Before and after

Mr. Shao gave his mother medication, he used the monitor to test her blood pressure to make sure the drugs had no side effects. Mr. Shao applied the oxygen machine when his mother had severe breathing difficulties accompanied her Parkinson freezing episodes. As in the above case of Mrs. Li (#051), Mr. Shao agreed with the importance of oxygen treatment in an emergency. He said, "Families should take necessary actions before 120 comes".[40] Since Shao's mother had been bedridden for more than ten years, Mr. Shao bought an air mattress to prevent bed sores. But occasionally, when relatives came to visit, Mr. Shao used a wheelchair to help his mother sit among relatives. He used another smaller wheelchair to move his mother from the "special care unit" to the bathroom. He also prepared another walker in the bathroom that could help his mother to stand up after she used the toilet. During nighttime and while bedridden, Shao's mother used the senior toilet seat nearby her adjustable bed. Mr. Shao felt the adjustable bed was specially designed for caregivers. Since the height could adjust, Mr. Shao could protect his back from getting hurt when lifting his mother out of bed every day. In order to maintain a stable temperature in the unit, Mr. Shao let the air conditioner run 24 hours a day. He explained:

> You see, most of these care devices are electronic, for example, the oxygen machine, the adjustable bed, the air conditioner, the air mattress, and other devices. I pay more than 1000 RMB [$140 USD] per month for the electricity fee. So, I have invested a lot in her care. These care tools cost me more than 10,000 RMB [$1400 USD]. I feel I should spend money to make sure she receives good care since she has given me her

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[40] 120 in China is equivalent to 911 in the US, i.e., the phone number of emergency medical care.

> pension and housing. If I do not create this unit, she has to constantly go to the hospital and it will cost more. If I use these tools to make sure her conditions remain stable, then, she does not need to go to the hospital and we can technically save a lot of money.

Not only did these technologies assist Mr. Shao to provide better care for his mother, but it also reinforced his reputation as a filial son in the community, a reputation that both his relatives and neighbors acknowledged.

Not all families can afford a "special care unit" for dementia sufferers. Nevertheless, family caregivers demonstrate their creativities when encountering care challenges. In Xue's family (#W16), Mrs. Xue and her husband took care of her mother who had been bedridden for twenty years. They had a very tiny room designed by Xue's husband, including a wide window, a bathroom, a small kitchen, and a hospital bed for the mother. Worthy of special attention was a care device that was made by Mrs. Xue's husband. Since the height of the bed could not be adjusted, he designed a supportive waist pad to protect against back injury. Inside of the pad was a steel plate; outside of the steel plate was the long-wearing leather pad. Putting these two components together provided a spinal support when getting the mother out of bed.

There were several other family caregivers who created everyday technologies. Mrs. Chao (#W18) took care of two bedridden parents for about ten years. She hung a rope on the beam that held up the loft area of their apartment. Each time her parents got out of bed, she pulled one of their hands and asked them to use the other hand to hang onto the rope. In this way, she saved a lot of energy and protected her back. Mr. Ding's (#W09) father was 101 years old. Due to his frailty, Mr. Ding needed to prevent him from falling while seated. He borrowed the concept of the safety belt, making one for his father's chair at home, and another for the wheelchair. Similarly, applying the pulley theory, Mr. Guo (#W10) designed a rehabilitation device for his wife to exercise her paralyzed arm at home. They lived in the fourth floor of an old building without elevators. Since his wife was handicapped on the right side of her body, she could not use the right-side handrails of the stairs. So, Mr. Guo hired some craftsmen to install a set of handrails on the left side of the stairs. In this way, Mrs. Guo could climb up and down stairs.

Not all family caregivers are crafts people. The availability of online shopping provides caregivers opportunities to deal with care challenges. The most popular shopping website/App in China is Taobao, which is equivalent to Amazon in the U.S. Taobao aggregates millions of shops and argues that it sells almost everything that you might need for daily life. During my fieldwork, almost all family caregivers had experience shopping online or using products bought by their children. The aforementioned care instruments together with other daily necessities—such as adult diapers, foods, kitchen tools, etc., discussed in more detail in the next section--can be bought online. Taking care of dementia sufferers often means family caregivers cannot go out shopping. As a result, online shopping becomes an important avenue to get necessities.

High-tech, everyday technologies, home-made devices, and online shopping not only assist family caregivers during care practices, but also improve the quality of life of dementia sufferers. Moreover, these technologies symbolize mortality and life, challenges and strategies, as well as continuity and change. Mrs. Fan, the Xue couple, Mrs. Chao, Mr. Ding, and Mr. Guo are all technogenarians who designed care devices to fit their needs; and to maintain lifelong continuity, control, and wellbeing. Each family caregiver uses these various devices to reduce hospital readmission. Given this context, home becomes a “home-hospital” that extends professional care to domestic settings. Correspondingly, family caregivers—who have already provided a widening array of health-related care and daily life support—are transforming their care practices from informal caregiving to formal services that should be acknowledged by various stakeholders.

Monitoring in and out: kitchen and toileting technologies

As dementia progresses, the greatest care challenge is managing and monitoring the food and drinks that go in the body, and the urine and stool that leave the body. Kitchen technologies such as blenders, slow cookers, kettles, and stoves are key instruments for preparing nutritional food. Equally important are toileting equipment such as senior toilet seats, traditional Chinese night stools, glycerin enemas, diapers, urine collectors, etc. As with the aforementioned high- and low-end technologies, these tools are associated with challenges, but can also elicit creativity. Such tools, many of which have been integrated into patients’ daily lives (even before the onset of dementia), provide continuity over the course of a day and a life.

Food preparation is a process that can be challenging but also creative. When I arrived at Mrs. Li’s (#W35) home for an interview, she was cooking with a protective eyewear. After I was seated, she explained her “cool glasses.” Mrs. Li’s husband had moderate dementia for about ten years. Recently, she and her husband had both had cataract surgery. After the surgery, they ordered takeout food for a couple of days during the transition, but her husband did not like the food. In order to make sure that her husband would have enough nutrition to “prevent brain atrophy,” Mrs. Li decided to cook by herself. But she needed to protect her eyes by wearing the “cool glasses”. Moreover, Mrs. Li developed her own food therapy philosophy: what she termed a “balanced diet” took into account not only biomedical ideas of nutrition, but also a balance of tastes, colors, smells, and textures. After years of cooking, Mrs. Li could prepare more than ten types of shrimp and fish for her husband.

Some family caregivers expressed that slow cookers and blenders were their favorite kitchen technologies for food preparation. For example, Mrs. Wang (#100), taking care of her mother with dementia, utilized an electric slow cooker to prepare a special porridge before she went to bed. The porridge, including different types of rice, two walnuts, 10g ginseng, and at least three types of vegetables, had to be cooked overnight. Since her mother had lost her teeth, Mrs. Wang used a blender to liquefy the porridge again in the morning. She also used a “water stew” to steam an egg to make sure her mother had enough protein. The porridge and the steamed egg were her mother’s breakfast. At noon, Mrs. Wang added 15g chicken/beef/shrimp/fish in the porridge for protein. Mrs. Wang used another high-voltage blender which could chop bones and meat so that her mother could swallow them. The dinner was the porridge with two types of fruits and a small cup of yogurt. Mrs. Wang said since she managed her mother’s meals very well, her mother could maintain continence and had regular bowl movements.

Mrs. Xu (#055) described how she used a blender and a kettle to prepare nutritional breakfasts for her mother. She explained, “The first thing I do is turn on the kettle and get some hot water. I need the hot water to prepare oatmeal, wolfberry powder, red-bean powder, and glutinous-rice powder. I then use the blender to mix the powders, and later boil an egg. That’s the breakfast.” Mrs. Xu also bought various healthcare supplements to make sure her mother receive essential nutrients, including protein powder and ginseng jelly. Since her mother could eat very little at a time, Mrs. Xu used the kettle to prepare liquid food and feed her mother every two hours to ensure she got both nutrition and fluids. She said, “Even if my mother cannot recognize our family members, she can live for a long time if I take good care of her.”

While acknowledging the importance of nutrition for dementia sufferers, many family caregivers also noticed that the onset of dementia and age-related changes in the appetite affected the diet habits of those they cared for. Some reported their kin ate too much, other reported that their taste changed. Mr. Sun (#021) said his wife’s eating habits changed a lot. Previously, Mrs. Sun ate very little. Since developing dementia, she would eat about one pound of rice at each meal. This happens a lot because she would forget that she had eaten. Therefore, Mr. Sun had to reduce the amount of food Mrs. Sun ate every day. Sometimes, Mrs. Sun would cry that Mr. Sun did not give her food. But, Mr. Sun knew that he had to control her diet not only to prevent diabetes and other diseases, but also to keep her regular bowel movements. Mrs. Hua (#W21) also complained of her husband’s changing eating habits. Previously, Mr. Hua had a balanced diet. Since being diagnosed with dementia, he only ate seafood, especially crabs. In order to make sure Mr. Hua had a balanced diet, Mrs. Hua often had to lie and tell him that crabs were expensive and they could not afford it.

Family caregivers have to adopt another set of technologies to deal with the changing toilet habits associated with aging and diet. Mrs. Xue’s (#W16) mother developed a taste for strong flavors after she developed dementia. This meant that she would only eat spicy foods. Her changing diet habits were followed by constipation. Mrs. Xue had to massage her mother's belly to facilitate bowel movements. Yet, sometimes this did not help. Mrs. Xue then used latex gloves to dig the feces out of her mother's rectum. Mrs. Huang (#W31) paid more attention to her mother's stool than diet since her mother was 92 years old and too frail to consistently have an unaided bowel movement. She let her mother use a bedpan or commode to see if her mother would be able to go, but if she could not, manual evacuation was needed. Mrs. Xue first inserted several glycerin enemas, laid a diaper under her mother's rear, and then put her finger gently into the rectum to pull the feces out. She said, "If stool is not emptied for several days, her life would be in danger," as fecal impaction is a serious health emergency.

Monitoring the amount of urine and preventing urinary tract infection are equally important. Mrs. Liu (#W13) gave her husband about 300 ml of water every two hours during the day and used a men's urine collection device to measure how much urine he excreted every day. Senior men's urine problems are relatively easy to deal with due to their physical advantage of having less surface area vulnerable to infection. Senior women are at high risk of a urinary tract infection due to their anatomy. Mrs. Xue (#W07), who was taking care of her mother, combined an old chair with a hole in the seat and a white plastic basin as a toilet bowl to monitor her mother's urine. She could judge whether her mother had a urinary tract infection based on the color and smell. During the night, she had her mother use diapers so that both of them could sleep without interruptions. A disadvantage of diaper use was that not all adult diapers were good quality, and they sometimes caused skin irritation. Mrs. Sun (#W04), for example, had to try several different brands of adult diapers for her husband since he had sensitive skin.

Bathing is another important care task. Patients living in modern buildings take regular baths. Family caregivers often use a plastic bath chair to enable patients to sit while bathing. Usually, two family members are needed to bathe a bedridden patient: one to keep the patient safe and comfortable, and the other to bath him/her. Comparatively, bathing for people living in old buildings is much harder due to the lack of private bathrooms. Even though the Shanghai government has done many housing modification projects to improve public sanitation, many families living there still have no access to private bathrooms. Among the 144 families in interviewed, there were about 20 families without access to private bathrooms. For those living in old buildings with private bathrooms, some functioned either as a toilet or as a bathing area due to the lack of a specific sewage pipe. These families had to figure out alternative way to bathe. Mr. Guo and his wife (#W10) lived in an old building. Originally, their bathroom could only bathe without a toilet. When he heard that they could install an electronic toilet, he paid two thousand yuan to install one. However, this electronic toilet often broke. He eventually called the Shanghai government to report how hard it was for them—as a handicapped old couple—to live in the old building without a reliable toilet. The local government later helped them to install a toilet. Not all family caregivers could solve the bathroom issue like Mr. Guo did. Some had to rely on traditional ways to bath, such as a large plastic basin at home or a public bathroom.

This section reveals how kitchen and toileting technologies organize daily care routines and enable family caregivers to continue daily care practices at home. Kitchen devices used here serve a wide range of goals, including balancing diet, maintaining continence, nourishing the body, and preventing other diseases. Toileting experiences also convey the multidimensionality of care and health via different tools. For dementia sufferers late in life, family caregivers must monitor the toilet behaviors to renew the body, to ensure comfort, and to maintain continuity. The bath unit with different functions not only helps family caregivers to keep their kin clean and in dignity, but also provides an opportunity for them to negotiate with the government for a better living environment.

Strategies for balancing safety and freedom at home and outside

Safety is crucial for dementia sufferers, not only in the home (bathrooms, kitchen, living room, and bedroom), but also outside of the home (getting lost and falling). Equally important is the freedom that people living with dementia continue to value highly. In order to balance these two principles, family caregivers incorporate various techniques into daily care, including monitoring systems, GPS, and name cards. These tools are both strategies to ensure dementia sufferers' safety and freedom (although limited), and to connect care receivers and family caregivers.

Traditional Chinese culture is risk averse, which affects dementia care. For example, caregivers would not allow frail family members to walk around at home because of the high risk of falling. Despite the onset of illness, many people living with dementia still desire freedom of movement. Family caregivers, particularly those with work duties, install a security camera to monitor their kin's safety. Mr. Zhang (#106), who took care of his mother, said the camera was an instrument that his family could not live without. His mother had moderate dementia and lost her ability to cook, nevertheless, she insisted on cooking. Through the monitoring system, Mr. Zhang found his mother often forgot to turn off the gas when cooking alone. This was dangerous since all other family members had to work during the day. Mr. Zhang therefore had to turn off the main switch of the gas to keep the home safe. Mr. Zhang also found that his mother often used a bowl to catch water in the bathroom for drinking. The water is not portable and needs boiling before consuming in China. Every time Mr. Zhang saw his mother drinking from the tap, he would call and tell his mother to stop. Sometimes it worked, but often it did not help, since his mother could not tell the bathroom from the kitchen. Mr. Zhang had to decorate the home by using bright colored paper and food symbols to remind his mother where the kitchen and toilet were.

Not only does the monitor help family caregivers identify care challenges and modify home settings to solve them, but it also saves patients during emergencies. Mrs. Mo (#W37) installed a monitor system to watch her mother at home. Her mother had middle stage dementia but could still move around at home. During the day, she often stayed in her bedroom with food and drinks. Mrs. Mo put a senior toilet seat in her bedroom, but her mother did not like using it, insisting on using the bathroom. Mo's mother risked falling on the way to the bathroom because it was far away from her bedroom. Mo once saw that her mother had fallen on the monitor and immediately went back home to check her status.

In order to prevent falls, Mr. Lu (#022) bought his mother a pair of shoes that were designed especially for seniors. He also bought several carpet squares to cover some spaces of his mother's bedroom, the living room, and even the bathroom. This home decoration might not surprise Westerners, but it was rare to see in many average families in China. Mr. Shi (#102) exchanged all armless chairs with armed chairs to prevent his mother falling. He also installed handrails surrounding the wall to make sure his mother could reach something to support her as she moved around the home.

It is also common for family caregivers to modify doors, windows, and the kitchen. Mrs. Zhen (#071) exchanged her front door with a security door with interior and exterior locks after her husband got lost. Given dementia sufferers' declining space-orientation ability, many family caregivers prioritized safety over freedom. In addition to the door modification, Mrs. Zhen had to lock the kitchen door to make sure her husband would not hurt himself or damage the home when she was out. Similarly, Mrs. Xu (#047) installed guardrails on the windows to ensure her husband's safety at home. Moreover, after learning that dementia sufferers might hurt themselves and others, Mrs. Xu hid sharp instruments at home, such as knives, to avoid unnecessary injuries.

Many family caregivers equip people with dementia with GPS trackers to monitor their location. There are many types of GPS available on the market. The lifetime of batteries is the primary concern for family caregivers since some types of GPS use batteries that can only last for several days. The most popular brand is the Millet bracelet, which has a long-lasting battery. Mrs. Yu (#063) bought her husband a GPS bracelet that only held a charge for three days. One day Mr. Yu went out wearing the bracelet. Unfortunately, the battery was dead when he got lost. Mrs. Yu had to seek help from policemen. In order to enable policemen to easily identify the home address, Mrs. Yu also used a traditional technique—the name card—to write down her contact information. Using a card holder, the name card was attached to his clothes—a popular practice for students and factory workers in China in the 1990s. Some people with dementia resisted any items hanging on their clothes or hands. In that case, caregivers wrote their contact information on the back side of their kin's coat. In order to protect their privacy, some caregivers wrote on the inside of the collar. Although it was ugly, people on the street can easily find the contact information when their kin get lost. A 74-years old wife (#036) taking care of her husband placed a piece of paper with their home address and phone numbers into her husband's wallet to save his life if he got lost.

This section demonstrates that family caregivers incorporate various modern technologies (e.g., monitors, GPS, etc.) and traditional strategies to ensure dementia sufferers' safety and freedom at home and outside. Despite losing some cognitive abilities, people living with dementia still try to control their activities and manage their own lives. Family caregivers have to modify home settings to help patients live as independently as possible. Meanwhile, they also have to evaluate potential threats at home and outside and take necessary precautions. Therefore, dementia sufferers' freedom has to be sacrificed to ensure their safety, a philosophy of good care that family caregivers endorse.

Use of information and communication technologies during caregiving

Computers, smart phones, televisions, radios, and Internet-based social media such as WeChat, MicroClinic, and online shopping Apps, are top technologies that most family caregivers rely on, particularly for those who value social connections, creativity, and self-support. These various information and communication technologies help family caregivers not only to find solutions that fit patients' needs and improve their care outcomes, but also to maintain connections with the outside world. Consequently, the incorporation of these modern technologies during caregiving further blurs the boundaries between home and society, and between individual and collective.

Information technologies hold instrumental meanings associated with social inclusion and intellectual agility. Most family caregivers I interviewed agreed on the importance of information technology. Mrs. Li (#003) taking care of her husband, watched the nightly news on CCTV-4, and Mrs. Lin (#094) listened to the six o'clock morning news on radio. They both said these technologies fostered their intellectual growth by association. Likewise, Mr. Wang (#W26), who had to stay home to take care of his wife, used the computer and Internet to search for news after completing his daily care tasks. Since they had to take care of their spouses, all acknowledged that the information technology—televisions, computers, Internet, and radios—kept them in touch with the outside world.

Family caregivers also utilized various information technologies to manage the health of their kin. After seeing the movie *Sister Tao* (a popular 2012 movie about a senior with dementia in mainland China), Mrs. Yao (#025) wonder if her father had dementia. She used the Internet to search for the information about disease. She also used the App MicroClinic to find the best memory clinics in Shanghai and China, and made appointments for her father. Similarly, after consulting with doctors and learning that music could help his mother's illness, Mr. Li (#028) downloaded a lot of opera music from the Internet for his mother. By continuing her life-long hobby of opera music, Mr. Li's mother improved her memory.

Information and communication technologies are key tools for self-care and family connection. Mrs. Hua (#001) was diagnosed with early-stage dementia but she insisted on self-care. In order to manage her illness, she actively learned various skills, such as photo-taking and -editing. After she finished photo-editing, she sent the photos to her granddaughter abroad via Internet. Mrs. Hua also actively learned how to use smartphone and WeChat. With these technologies, she could share photos with her family and friends and talk to them when possible. She said, “I feel the distance between my family members and I is shorter than before.”

While Mrs. Hua used information and communication technologies to maintain self-care and family connections, Mrs. Shen turned to these technologies to coordinate care and social support. Mrs. Shen (#056) and her three siblings took turns caring for their mother. She adopted early intervention strategies because she thought she might belong to the high risk population of dementia. She actively learned new skills to sharpen her mind, including online shopping, Alipay, P2P Finance, etc. She downloaded a shopping App and learned how to buy fresh vegetables online. Considering she had limited opportunities to shop outside, Mrs. Shen felt these skills were very important for her to coordinate care and daily life activities.

WeChat is an important social media service that not only links people together, but also provides information for various groups. This App combines the functions of Skype, WhatsApp, Paypal, Facebook, Twitter, and other public services all in one platform. Some public accounts of WeChat provide disease information, which have drawn great attention from many family caregivers. With this App, Mrs. Zhen (#071) initiated an online support group—Family Dementia Caregivers’ Mutual Support Group. There were more than a hundred family caregivers in her online group. Not only did they actively share disease information with other friends and caregivers, but also created a supportive online environment. She said, “When I heard my husband was diagnosed with dementia, I felt my life was over. But now, I gradually adapt to it. I do not feel lonely anymore after we organized a WeChat group. We often express our feelings to other family caregivers who have similar experiences. Sometimes we share information about social policies, such as disability benefits.” Information technologies such as WeChat provide a unique form of free social support for family caregivers that falls outside of home and professional services.

WeChat is more than a tool for keeping people connected and providing mutual support among family caregivers. It is also a platform to negotiate an identity and to legitimize one’s work. Without acknowledgement of the sacrifices they made for society, many family caregivers relied on WeChat as a way to publicize the multiplicity of care work. Some family caregivers took photos about daily care practices, e.g., memory training, sightseeing, and family gathering. Recording these moments made them feel that they were part of something larger than themselves, they were needed, and their lives were worthy. Family caregivers who added my WeChat account often showed me their daily activities or directly uploaded their photos into a public space. Friends clicked the “Like” button to cheer them up. Some family caregivers used WeChat to announce the death of their kin. At that moment, friends would show empathy to and concerns for them. There were also family members who wrote about their thoughts and ideas at specific moments while caregiving. For example, a family caregiver recorded that when other family members were discussing the US-China trade war during dinner time, his father—who suffered from dementia for many years and barely spoke—suddenly “woke up” and advised them to fight against US and win the war. Sometimes caregivers used WeChat as a tool to release their emotions. As Mrs. Chen (#086) said, “I do all the care work, but nobody talks to me at home. I wrote these words to let the built-in negative energy out. If not, I will be depressed.” Through WeChat, family caregivers have the opportunity to reveal the physical and emotional labors involved in daily care practices, which provides an avenue for them to articulate their social identity and social worth.

Information and communication technologies offer a sense of social connection, family closeness, and mutual support for caregivers. They also serve as medical information technology as well as easy-to-learn communication tools. Due to limited state support, the fear and anxiety associated with dementia, and the necessity of meaning-making, family caregivers actively adopt these technologies in their care practices. Equipping with these technologies, family caregivers can continue both their social roles and family responsibilities.

Care as Stewardship within the Context of Family Dementia Caregiving

The starting point of this chapter is to emphasize family caregivers' agency in care practices to supplement existing literatures on care. I have discussed the practical arrangements of everyday technologies and activities: pharmaceutical care; mind stimulation techniques; high- and low-end technologies to tend to the body; kitchen and toileting technologies; safety technologies; and information and communication technologies. This list is a convenience—in practice, the multiplicity of care and its coordination is much larger. Family caregivers care for: dementia sufferers at the point of their emergency, suffering, and death; other family members in need of support such as child-care and grandchild-care; caregivers' own health and needs; and their neighbors and community events. All of these activities entail family caregivers' active application of a broad range of modern technologies to ensure a list of compartmentalized events to do in a way that is timely coherent and efficient.

Analysis of the agency of family caregivers opens up a different conception of care. In this case, care is stewardship, carried out by family caregivers who incorporate various social resources—biomedicine, alternative medical care, and everyday technologies—to improve dementia sufferers' health outcomes. Emphasizing care as stewardship means that care is not only a set of materially heterogeneous practices involving different kinds of subjectivities, activities, instruments, and technologies (Loe 2010; Mol 2008; Mol et al. 2010), but also an ethic that takes into account avoiding suffering and management of these material aspects of life. I use the word "stewardship" to invoke the performativity of family caregivers as well as their moral reasoning during caregiving. To care is to meticulously explore, test, adjust, adapt, and focus until a desirable outcome has been achieved. Stewardship in dementia caregiving involves an assessment of "good" and "bad" treatments; a transformation of what everyday activities are; an incorporation of the technology and instruments; and a reestablishment of the ways in which people are linked to one another. All are crucial to good care.

The agency of family caregivers is an important dimension of care as stewardship. There are similarities and differences between agency theory and the stewardship approach to caregiving. Agency theory focuses on individual independency and free choices within particular social structures, which positions agents in contrast to the state (Kiser 1999; Shapiro 2005; Weber 1924/1978). An agent is motivated by personal interests and extrinsic rewards. While the stewardship approach also acknowledges the power distance between agents and the state, it emphasizes the self-efficacy of agents (Armstrong 1997; Kass 1990; Saltman and Ferroussier-Davis 2000). That is, agents—based on their personal abilities and creativities—incorporate various social resources to reduce their power distances with the state. Therefore, stewardship—an explicitly ethically-based approach—is substantially more outcome-oriented and intrinsically motivated. Agency theory and the stewardship approach are not necessarily mutually exclusive; they are mutually imbricated. Take family caregiving for example. First, a family caregiver should be identified as an agent in order to react to the surrounding environment, e.g., the needs of dementia patients and customs of care practices. Then, the agency of a family caregiver is more likely to depend on the situation, i.e., economic conditions, the availability of everyday technologies, and the accessibility of care devices. Finally, the expectations of both caregivers and care recipients are also involved in decision-making. The choice of a family caregiver is circumscribed by ethically motivations, which provides the gap between agency theory and stewardship approach.

In the context of dementia care, care as stewardship requires a balance between efficient-oriented care practices and ethical-based decision-making. It is obvious that there are moments when "good" care requires particular elements be brought together: pharmaceutical care and everyday memory training; prescription drugs and patient monitoring; high-tech care instruments and home-made care devices; nutrition and the taste of food; prevention of incontinence and application of toileting techniques; the balance between safety and freedom; and in-home care and transporting technologies. If, as Mol has argued (2008), care is an unfolding embodied and material process, then the stewardship of these multiple moments of care is central to its organization. In other words, stewardship is the appropriate basis on which to resolve these dilemmas and reconfigure the role of technologies during caregiving. At the same time, it is also important to note that the unfolding of stewardship of caregiving is more or less local, for the illness conditions of dementia sufferers and their surrounding environments cannot be predicted. Care depends not so much on a formula that allows situated actions to happen, but more on caregivers' creativity, agency, and stewardship.

Stewardship also entails trustworthiness between those who are caregivers and those who are care receivers, which enables multiple roles for family caregivers. This is particularly important in the context of caregiving since most elders with dementia lost their cognitive and physical abilities in later life. Since there are various social services (albeit inadequate) for elders with dementia in Shanghai, family caregivers are the ones who navigate the healthcare system and the social eldercare system to find the "best" services and bridge them to their kin. Family caregivers also have to modify the surrounding environment and select devices to achieve the goal of "good" care. When family resources are limited, they have to extend their imaginations and creativities beyond environmental constraints by crafting the most suitable care devices. They also monitor dementia symptoms and protect patients from being prescribed antipsychotic medications absent a valid, clinical indication. When in need of biomedical care, they evaluate the pros and cons of prescriptions and utilize multidimensional strategies to minimize the side effects of drugs. In special situations such as emergency care, family caregivers become surrogate decision-makers. Therefore, family caregivers are simultaneously service hunters, resource coordinators, 24/7/365 nursing providers, "half doctors," technogenarians, craftsmen, and surrogate decision-makers. These multiple roles of caregivers as well as the broadness of these roles outline the unique position of family caregivers in our societies. Moreover, the complex roles, sets of responsibilities, and underlying trust between caregivers and care recipients are inherent in the concept of stewardship.

An examination of family caregivers' agency in selecting and deploying appropriate everyday technologies reveals an attractive attribute of the stewardship approach—its capacity to integrate the efficiency-oriented care technologies with morally-based care values. While acknowledging that advances in technology have addressed a variety of health concerns for the aging population such as prevention, detection, and treatment, scholars also point out that these technologies create social stratification by favoring those who are economically advantaged (Drori 2006; Warschauer 2003; Weiss, et al. 2018). Although fierce debates continue to rage over the impact of science and technology on our societies, most analysts of welfare states now regard a rigidly technical style of services for human beings as counterproductive in the fields of healthcare and eldercare. Yet, to go to the other extreme and eschew scientific knowledge and technologies in favor of pure, natural, loving care is not the answer in the case of family based dementia care. Within the global context of population aging, a stewardship approach to the intersection of caregiving and technology may help to promote new, more socially responsible systems of integrated care.

Chapter 6 Resigned Familism: The Burden Discourse of Dementia Care

After taking care of her husband who suffered from vascular dementia for ten years, Mrs. Gu hanged herself on the night of June 10th, 2017. She was found by her son the next morning. News of this tragedy was quickly reached to her niece, Mrs. Shen, who was taking care of her mother. According to Mrs. Shen, her aunt, Mrs. Gu, had a good relationship with her two sons and one daughter. Her three adult children all had established families and their own careers. Mrs. Gu was also in a good economic circumstances. In addition to her and her husband's pensions, she was compensated about 70,000 RMB [$9,800 USD] from the state during a land acquisition. Therefore, her death was probably not due to economic concerns. Mrs. Gu's suicide, according to Mrs. Shen, could be due to years of care burden that fell exclusively on herself. Her three children had contributed little to help Mrs. Gu to take care of her husband. Her family members did not take a serious attitude toward Mrs. Gu's years of caregiving. Her children believed that it was her "natural" responsibility, rather than a burden, to take care of their father. Before Mrs. Gu hanged herself, she wrote several notes to all of her family members. The one she wrote to Mrs. Shen was, "Life is too hard, too hard, and too hard *(huozhe tainan, tainan, tainan).*"

The death of Mrs. Gu could be due to long-term caregiving-related depression from a psychological perspective. Psychological and sociological studies have reported elevated levels of depressive symptoms among caregivers, and those using diagnostic interviews have reported high rates of clinical depression and anxiety (Borsje et al. 2016; Mausbach et al. 2013; Omranifard et al. 2018; Riley et al. 2014). My dissertation findings also demonstrate this relationship: almost all family caregivers reported anxiety and depressive symptoms such as insomnia associated with caregiving. Poor physical health conditions were also frequently mentioned by family caregivers, including various chronic illnesses and lack of time for self-care. A number of studies have linked the poor health conditions of family caregivers with the increased care burden associated with patients, such as the severity of disease, the frequency and intensity of care, and (the) lack of social support (Farina et al. 2017; Robison et al. 2009; Schulz and Martire 2004).

While acknowledging that taking care of dementia sufferers is challenging, I aim to explore this phenomenon from an anthropological perspective. That is, what is the burden discourse –to use the phrase of so-and-so - of family dementia caregiving? Particularly, what constitutes and causes the burden of dementia care in Shanghai? How do biopolitical discourses such as stigma affect the perceptions and practices of dementia care? How does the burden discourse affect traditional forms of care that are based on generational interdependence, and vice versa? Why does the social support fail to mitigate the burden of family dementia caregiving in Shanghai?

In the previous chapter, I discussed how family caregivers endorsed care as stewardship by engaging in medicine and modern technology to improve care outcomes. In this chapter, I continue to explore challenges of family-based dementia care. More specifically, I argue that the legislation that requires families to take responsibility for eldercare, the medicalization with stigmatization of dementia, and the inadequate family and social support have created what I call a *resigned familism*. Family caregivers engaged in this form of care are neither fully resigned nor fully compassionate, and they often maintain ambivalent feelings about their care practices. Mrs. Gu in the above vignette is a testimony to resigned familism. She did not give up taking care of her husband during the ten years, but Mrs. Gu's suicide also demonstrated that she was not happy with her long-term caregiving. Some family caregivers reject medicine and modern technology. Their rejection questions biological causality of dementia and the effectiveness of modern technology on the one hand, and the intimate relationship between dementia sufferers and family caregivers on the other. Resigned familism creates new forms of organizing care, and these new forms of care in turn reinforce resigned familism.

Emphasizing resigned familism does not necessarily reject the concept of care as stewardship since they both reflect various understandings of dementia and approaches of care. While both invoke the performativity of family caregivers, care as stewardship emphasizes their agency and care ethics, whereas resigned familism focuses on the burden of family dementia care and the ensuing effects. These effects are often negative, such as family caregivers' rejection of medicine and modern technology, their helplessness in the face of stigma, and the low self-efficacy to deal with the burden. Resulting from various factors, resigned familism sheds light on the burden discourse of dementia care, including folk understandings of dementia, family estrangement, and inadequate social support.

In this chapter, I first contextualize resigned familism by examining local idioms related to dementia and dementia care. These local idioms not only demonstrate a different arrangement of dementia care, but they also serve as the direct causes of resigned familism. I further examine two contributing factors and their influences on care practices - family estrangement and inadequate social support. These are both indirect causes of resigned familism. Family caregivers who endorse resigned familism often find the experience of taking care of dementia sufferers to be a desperate challenge. Thus, analyzing the causes of resigned familism will shed light on the burden discourse of family dementia caregiving.

The Context of Resigned Familism

Resigned familism is directly caused by Chinese legislation, which emphasizes family responsibility for eldercare, and the stigmatization of dementia, which discredits family's efforts of caregiving. In other words, family caregiving for elders with dementia is valued neither by society nor the family, given the economic-centered political atmosphere in Shanghai. As a result, family caregivers endorse negative attitudes toward dementia care, such as a feeling that there is no solution, or *wang si wang* in Chinese term. Folk understandings, such as *tianshu*, and *baoying* (as I will discuss below), further contextualize resigned familism due to the limits of biomedicine. Terms used to describe dementia are cultural codes that activate the stigma associated with dementia and dementia care. The state's enactment of family responsibility further intensifies resigned familism because it reinforces family-based care without acknowledging its social values. According to the mandate, challenges associated with eldercare should be solved only by the family itself. Family caregiving, both a cultural and a legal practice, is not worthwhile to discuss in public settings. The medicalization and stigmatization of dementia, as well as Chinese legislation of family responsibility for eldercare, co-construct resigned familism.

Wang si wang

Wang si wang is a local idiom in Shanghai, which I often heard from family caregivers[41]. It denotes a negative situation that causes people to be miserable and sad. When people have no confidence to deal with challenges, they often use this term to express their attitude. Literary translations can be "that's it," "there is no solution," or "I cannot do anything."

Family caregivers often use this term to express their frustrations of living with dementia sufferers. For example, Mrs. Zhou (#007) had been taking care of her mother for almost five years. Unlike other family caregivers, Mrs. Zhou did not give her mother any medicine even though the mother had health insurance, nor did she try to improve care outcome by engaging in modern technology. According to Mrs. Zhou, "If biomedicine cannot cure this disease, why should we spend money on drugs?" When I explained that taking drugs could ameliorate dementia conditions and improve the quality of life for her mother, she continued to doubt the effectiveness of drugs based on the previous treatment. Mrs. Zhou's frustration with her mother's dementia also came from her poor relationship with neighbors. When neighbors hung out their clothes to dry, her mother often confused about that and would take these clothes home. Neighbors often complained about her mother's "stealing" behavior and gossiped behind Mrs. Zhou. When some people reported the gossip to her, Mrs. Zhou became so angry that she had no willingness to devote time to care. Because of the stigma, Mrs. Zhou had no intention to explain the situation to her neighbors. As a result, she tried to reduce the opportunities for her mother to go outside. When I asked her whether she knew about the negative impact if her mother was constrained at home, Mrs. Zhou said, "I certainly know. How

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[41] There is no written Chinese character for this phrase.

can I deal with our neighbors' rumors!? I can only *wang si wang*!" Unlike other family caregivers who paid more attention to dementia sufferers than others, Mrs. Zhou valued a harmonious relationship with her neighbors than the care outcome. She felt frustrated when her mother interrupted this social order. By subordinating her value to the harmonious relationship, she tried her best to minimize the interruption, rather than improving care outcome.

Family caregivers' attitude of *wang si wang* also comes from patients' resistance to any medical treatment. Mrs. Yu (#W11) had been taking care of her husband for about ten years. Her husband, Mr. Yu, had obvious cognitive impairment. He refused to get a diagnosis and any treatment, even though Mrs. Yu had personal connections with some physicians. What made care so challenging was that Mr. Yu could not sleep overnight, which caused his wife to also be sleepless and feel tired all day long. Moreover, because his cognitive abilities continued to deteriorate, Mr. Yu started to soil his pants. Sometimes he defecated in front of their neighbors, which often caused rumors to spread in the neighborhood. When I visited this family at their home, Mr. Yu sat in the sofa and was drinking a large bottle of coca with sugar. Mrs. Yu told me that her husband also had diabetes but refused to adopt any strategies for dealing with it. I felt it was a risk for him to continue this unhealthy diet. So, I invited Mr. Yu to join a community health program. Mr. Yu, even though he had cognitive impairment, politely rejected. When I told him that I had a personal connection with a prestigious doctor who could improve his illness, Mr. Yu argued with me that he was completely fine. Mrs. Yu whispered to me:

> All of our families have tried to persuade him to see a doctor, but failed. We had many quarrels about taking care of him. My children even

> deceived him to get free treatment, and it’s useless, either. He will not see doctors. He completely ruins himself, our family, and our neighbors. The Residents’ Committee talked to me about his pooping behavior in the public space. I could only explain to them that he had dementia. What else can I do? *Wang si wang*!

Her husband’s resistance to medical care made Mrs. Yu resign herself from fully taking care of him. Her failed care, such as her husband’s pooping behavior in the public space, and the involvement of the Residents’ Committee, further challenged Mrs. Yu being a morally responsible person. In Western societies, people believe that patients have their right to decide whether they should get treatment. In societies dominated by Confucian values, however, patients, especially those with mental illness or cancer, have subordinated their autonomy—such as making decisions—to their families (Fan and Li 2004; Lee 2019). It is family responsibility to ensure patients access to medical treatment and other forms of care. The respect for patients’ autonomy in Western society becomes a dilemma of family caregivers in Chinese culture. Mrs. Yu felt that she had the moral responsibility to take care of her husband; however, her husband’s resistance to any medical treatment reduced her to be a morally irresponsible person.

Mrs. Yu’s attitude of *wang si wang* also comes from her moral dilemma regarding competing benefits between her husband and her son. When I asked Mrs. Yu about the possibility of sending her husband to a nursing home, she continued to whisper to me about the harsh condition of this family. Her son was divorced several years ago. Her ex-daughter-in-law took an advantage and retained the housing property that should belonged to the young couple. Since the divorce, the son had to live with the old couple due to his limited income. Mrs. Yu had to save money to help her son reestablish a family, which meant to buy another apartment. Therefore, Mrs. Yu had to balance her husband's needs for better care and her son's needs for an apartment when family resources were limited.

Folk Knowledge of Dementia

Folk knowledge about illnesses often arises when biomedicine fails or is ineffective in treatment. Here, I focus on two local idioms related to the causes of dementia, *tianshu* and *baoying,* which are often used by family caregivers to describe their powerlessness in the face of this illness. *Tianshu* comes from *The Book of Changes*, which is one of the ancient Chinese classics. It can roughly translate to "number of days," which means the natural order. People often use this term when they describe something that goes beyond one's ability of control. Associated with *tianshu* is *baoying*, which means retribution or karma. *Baoying* is a Buddhist term that is widely used in everyday life. Because dementia is an incurable and stigmatized disease in China, patients who suffer from dementia are considered as their *tianshu*, or an inevitable part of their fate. Family caregivers often use *baoying* to understand causes of their kin's suffering from dementia and their caregiving.

Mr. Lu's (#093) caregiving but shunning away from biomedical care directly captures the connection between *tianshu* and resigned familism. Mr. Lu had taken care of his wife for almost six years when we met in the memory clinic. Surprisingly, our interview was conducted during their first visit of the memory clinic. Unlike some family caregivers who often did not have the knowledge of dementia, Mr. Lu had accumulated certain experiences with dementia care. According to Mr. Lu, before he took care of his wife, he had helped her to take care of his father-in-law for almost four years, who also suffered from dementia. Mr. Lu continued to unfold another sad story that his wife's brother also suffered from dementia and died last year. When I asked him why they came to visit doctors so late, Mr. Lu explained to me:

> My father-in-law who suffered from this disease was treated by psychiatrists. They gave him many sedatives, and he became even more stupid and crazy. Eventually, he was physically constrained in the hospital. Her [his wife] family so far has three cases of dementia. I thought it might be *tianshu*, and it's better not to see doctors since they cannot help.

Mr. Lu's endorsement of *tianshu* not only justifies his action of shunning away from medical care, but also challenges the effectiveness of psychiatric care. The failed experience of seeking effective treatment also made him believe that developing dementia "might be *tianshu*." Without a biological solution, it was the fate of this family. Mrs. Lu was not the first case, nor was she the last one. In our conversation, Mr. Lu expressed his concerns whether his daughter, their only child, could have the genes to develop this disease. When I introduced the pros and cons of genetic test about Alzheimer's disease, Mr. Lu said, "It's better not to know. If we all know our genetic deficits, how can we continue to live in this world? It's so hard for us to accept this diagnosis. If our friends and colleagues know about that, they will look down upon us."

Mr. Lu's shunning of biomedical care was not only due to the ineffectiveness of treatment, but also due to the diagnosis and the meaning assigned to the illness, i.e., the genetic deficits of dementia. The Chinese people have long recognized the link between mental illness and heritage causes (Chapter 1). The fact that Mrs. Lu's natal family had a high incidence of dementia indeed reinforced this association. If people all knew about Mrs. Lu's diagnosis, then a lot of unnecessary misunderstandings would occur, such as being looked down upon. Mr. Lu was also worried about his daughter's potentiality of suffering from dementia, which demonstrated that he was fully aware of the potential genetic causes.

The folk knowledge of dementia is also evident in the term *baoying*, with which family caregivers reject any social support. Mrs. Li's (#003) husband was an upper-level government official. Her life was completely changed after her husband was diagnosed with dementia. Considering the potential misunderstanding, Mrs. Li did not release the diagnosis to any friends or colleagues. "Originally, he was a talented person. I still have no idea why it is him who has to suffer from this disease. People might gossip that his illness is a *baoying*, regardless of biological causes," said Mrs. Li. Because of her concern about the misunderstanding, she did not accept any social support. Similarly, Mrs. Xu (#055) rejected any support because her mother's dementia was caused by syphilis. As we all know, syphilis is a sexually transmitted disease, which has been stigmatized in China. The public also use *baoying* to describe prostitutes or any people with misbehaviors have to suffer sexually transmitted diseases. Mrs. Xu told me how shameful it was when the doctor told her that her mother's dementia was caused by syphilis:

> We literally could not say anything when the doctor told us about our mother's diagnosis. We know our parents could not get along with each other for a long time. My father often went out for fun [extramarital sex] when he was young. I could not believe my mother did that. Having such a

> disease is a *baoying*, and it’s better not to say anything and not to tell anybody. Only our siblings know the diagnosis. We don’t even dare to tell other family members, not to say to ask them to help.

The gap between biomedicine and folk knowledge of dementia often results in misunderstanding among the public. Despite the effort to raise public awareness of dementia in recent years, most Chinese people still rely upon folk knowledge to understand dementia, particularly when there is no curable treatment. The double stigma—sexually transmitted disease and dementia—reinforces the folk knowledge of *baoying* and the causes of dementia, which further prohibit family caregivers from seeking social support. Equally worth mentioning is that the public media also leads to a misrepresentative of dementia. Corresponding to Ramsay’s analysis (2013), I found media often portrayed dementia sufferers in late stage, highlighting effects such as incontinence, loss of independent living abilities, and inability to recognize their families. These portrayals do not end up with a proactive and empathetic response to sufferers from the public; rather, it raises the awareness of the poor self-efficacy of dementia patients, resulting in a prevailed negative attitude among the public.

Terminology-Related Stigma

Stigma is defined by Goffman (1963:3) as an “attribute, behavior or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one.” Individuals possessing such an attribute are different from others in ways that are undesired and shameful. Despite the increasing public awareness of dementia, patients and their family caregivers continue to be stigmatized in China. While acknowledging that stigma is a complex individual experience based on the manifestations of disease, social environment and structural factors are powerful elements to activate stigma.

In China, the terms of memory clinics serve as a structural factor that prevents family caregivers from seeking professional help. Chapter 1 investigated debates between conceptualization of dementia as a mental disorder and one as a neurodegenerative disease. These debates are closely related to structural factors that activate stigma. For instance, mental healthcare is a separated system from general healthcare in China. As a result, mental healthcare centers are separated from general hospitals. In other words, a patient with mental illness should go to mental healthcare centers for treatment rather than general hospitals because there are no such services. This service separation reinforces the structural stigma. Consequently, most family caregivers and dementia sufferers usually stay away from mental healthcare centers to avoid the diagnosis of psychiatric disease. In Shanghai, the only municipal Mental Healthcare Center is located at Xiaomuqiao Road 600. The Shanghai citizens often use "600" to label this institution, as Mr. Du (#010) stated the following:

> My mother strongly resists going to #600. My friend's father is also diagnosed with dementia, and he, too, resists going to #600. I know this disease should go to #600 for professional care. When I arrived there, what I found was Dementia Clinic (*chidai menzhen*, 痴呆门诊) and Mental Disorder Clinic (*jingshen zhangai menzhen*, 精神障碍门诊). I also dislike these names and the environment for treatment.

Another family caregiver, Mrs. Xi (#041) also mentioned that the name of the clinic took an account to reduce the potential stigma associated with this disease:

> I like the name "Memory Clinic" (*jiyili menzhen*, 记忆力门诊), which will not convey negative feelings for seniors. If it is a "Dementia Clinic" (*chidai menzhen*, 痴呆门诊), people who come over here will consider themselves as dementia patients, which is a big challenge. They will not come for sure.

In Shanghai, terms related to mental health services have gradually been institutionalized into accepted patterns of discourses, which shape our activities and practices (i.e., how we act) and social relationships and organizations (i.e., how we relate) (Kemmis and McTaggart 1988). Instead of using the official name, people often refer to the nick name or the road number, #600, to imply the specific social and physical position in Shanghai. Given the structural disadvantage, most dementia sufferers and their family caregivers in Shanghai refused to visit the Mental Health Center. Chapter 1 introduced the changing conceptualizations of dementia and approaches to dementia care in the medical field because of the associated stigma. Stigma equally prevents affected individuals from acknowledging their symptoms and seeking psychiatric care they need. As a result, stigma creates conditions where even well-intended institutions and organizations become unhelpful. For instance, mental healthcare centers and some memory clinics—which adopt poor terms to describe dementia—become places of "othering" patients. Rather than creating a supportive environment, these places emphasize the negative aspects of dementia and its symptoms and losses. More importantly, when people see and hear words such as "mental illness (*jingshen bing* 精神病)," "psychiatric disorders (*jingshenbing*, 精神病)," "dementia (*chidai* 痴呆)," "disorder (*zhangai* 障碍)," etc., they often have preconceived ideas and misconceptions of what the diagnosis represents. Negative social meanings are also linked to the person in those specific social places (e.g., mental healthcare centers) through a labelling process, and the person with dementia might internalize these meanings. Therefore, emotional responses created by these institutions might directly cause family caregivers and dementia sufferers to resign themselves from seeking professional care.

In addition to the structural stigma, the social environment for dementia sufferers and their family caregivers is unfriendly in China. The medical field label dementia as *laonian chidai* (老年痴呆), a poor word choice literally meaning old, "retarded," stupid, and crazy (Dai et al. 2013; Ramsay 2013). Based on my observation in public areas and my informants' responses, individuals often uttered this offensive term in anger or annoyance, which exemplified social discrimination to this group of people. Therefore, the unfriendly social environment for dementia sufferers can account for their fear of being diagnosed. For instance, Mrs. Hua (#001) resisted the label *laonian chidai* to describe her illness, because "people often use this derogatory term as a weapon to curse others."

The terms used among the public to describe dementia constantly remind us of the power of words, and how words shape our actions such as resigned familism. In Shanghai, the public describes dementia as "retard (*gangdu*[42])," "psychosis (*jingshen bing*, 精神病)," and "idiot (*baichi*, 白痴)," which fuels fear for this illness instead of expressing

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[42] There is no written Chinese character for this phrase.

compassion and empathy. Because of these terms associated with stigma, there is a strong resistance of labelling dementia as a mental illness among dementia sufferers and their family caregivers, as evidenced by the above cases. In some Asian countries, medical experts have to reevaluate dementia as a mental illness due to patients' resistance (Ticehurst 2001). For instance, in India, dementia was categorized as a neuro-related problem, not a mental problem because of the associated stigma (Nichter 2008; Brijnath 2014). In Japan, since the terminology of *chihô* (dementia) carried strong stigma of senile dementia, in 2004, the government renamed it with a prejudice-free term, replacing *chihô-shô* (dementia disease) with the term *ninchi-shô* (cognitive disease) (Ikeda and Roemer 2009). In China, although social media has proposed several times to rename dementia, significant stakeholders (e.g., medical professionals and government officials) have no imperatives to change the terminology of dementia so far, except that the Shanghai government of Civil Affairs decreed the prohibition of using discriminative terms in public space in 2018. Some scholars point to the fact that even though the indexing terms for dementia have been changed, the original diagnostic classification has not (Ikeda and Roemer 2009). Thus, social stigma of this illness still exists in Asian cultures.

Terminology-related stigma in China can be considered as an amalgamation of three related problems—a lack of disease knowledge, negative attitudes, and excluding or avoiding behavior—which reinforce resigned familism. It is clear that there are striking gaps about the knowledge of dementia. Even though the Shanghai government has initiated the project of building dementia-friendly communities, public education about dementia is limited, and misconceptions—such as *baoying* and *tianshu*—are widespread.

There is also evidence that negative attitudes act as barriers to seeking care. Individuals are required to be responsible for their own conditions, and therefore, people who are cognitively intact might be more likely to react to dementia sufferers with anger, pitilessness, and even avoidance. What makes things worse is that the discriminative terms used to describe dementia do not accurately represent the illness. The denotation and connotation of these idioms misleads the public that people living with dementia lack independence or social contribution even though they can maintain these abilities for a long time after dementia onset. Given the dominant culture that values cognitive functions, family caregivers also take negative attitude—*wang si wang*—to deal with dementia sufferers. In some cases, dementia sufferers are not taken seriously by their family members, and are often excluded from decision-making, group activities, and public events.

Caregivers' burden is highly associated with stigmatic beliefs in general and emotional shame reactions in particular. In Shanghai, although some communities have developed dementia care programs, most family caregivers for elders with dementia are out of reach due to various barriers. These barriers, in turn, reinforce the resigned familism. When neighbors or friends stop reaching out to dementia sufferers and their families, their support will drastically decrease. Family caregivers who engage in resigned familism may also isolate themselves from others or avoid participating in social activities. This might contribute to the poor health conditions of caregivers, e.g., depression, anxiety, and physical illness, all of which are likely to result in greater health care costs and other financial burdens. In the following sections, I will examine the depravation of support networks within both domestic settings and society, which indirectly contributes to resigned familism.

Family Estrangement and Resigned Familism

Dementia care challenges family relations late in life. Due to the intensive care burden, the progressive nature of this illness, and possibly the stigma, family conflicts constantly occur, which results in an estrangement among family members. Moreover, disagreements and perceived lack of support from family members exacerbate feelings of burden (Chan 2007; Sun 2014), which may cause resigned familism. In this section, I will discuss three types of relationships—sibling, intergenerational, and marital ties—that become estranged after a family member was diagnosed with dementia. While acknowledging that the onset of dementia sometimes brings family members together to work out solutions, there are also cases ended up with broken family ties, which in turn increase the perceived care burden. The estranged family relationships also correspond to the solo caregiving phenomenon in Chapter 4. In this chapter, I focus on how these three dynamic and delicate relationships directly cause family estrangement, which further contributes to resigned familism.

Estranged Siblings

Although spouses and adult children constitute primary caregivers, siblings are equally essential to enhance the quality of life for dementia sufferers. This is particularly important for people living with dementia since their long-term memory is often less unaffected than the short-term memory in the early stage of this illness. The importance of sibling relationships also lies in the way that they—together with other family members—create a bioecological niche to foster a social network in which one’s position and identity is defined and protected. The social network is meaningful when one is sick, and support from other members in the niche will provide a sense of familiarity. This kind of support becomes profoundly important when public services are limited and underdeveloped in traditional communities. For thousands of years in China, this bioecological niche prospers and functions within the context of Confucian values and beliefs. However, numerous studies have reported that rapid modernization has challenged the prosperity of this bioecological support from extended families (Ikels 2004; Jesmin et al. 2011; Santos and Harrell 2017; Traphagan 2000). Supplementing this finding, this study identifies the internal factors that facilitate the division between extended and nuclear families.

Dementia-related stigma is one potential factor that causes the estrangement between dementia sufferers and their siblings. Mrs. Li (#044) told me her experience of being estranged. Her husband, Mr. Li, was diagnosed with dementia about five years ago. Since Mr. Li had only one brother in his natal family, Mrs. Li contacted his brother and told him about the diagnosis. “I thought he could come over and visited us since my husband’s illness became severe,” said Mrs. Li. “Unfortunately, there was no phone calls and no messages. I haven’t seen him for several years, and we have no contacts during the Spring Festival. So, I think we have been estranged.” When I asked Mrs. Li about the potential causes of their estranged relationship, she had no idea except for the potential stigma: “I know it is hard to accept the diagnosis because of the stigma. If his brother saw him, what would he think about their family and our [nuclear] family? It’s better [for him] not to know.” Although there was no clear reason for their estranged relationship, Mrs. Li believed it could be related to the stigma. Distancing the Li couple was a solution to reject the "polluted" family (Cohen 1998) or hide oneself from the fact. Without an effective support from his brother-in-law, Mrs. Li said, "It's all about my work. I am now both a woman and a man! Sometimes I cannot control myself and yell at him. Why should I do all of these tasks that used to be men's work?" The dementia-related stigma further caused Mrs. Li to resign herself from fully devoting time to caregiving, because she had to work like "a woman and a man," to be a breadwinner and a caregiver at the same time.

In addition to the stigma, some family caregivers attributed their estrangement to the lack of affection among siblings. Mrs. Xu's (#047) husband had four siblings. Previously, they often gathered together monthly for meals. Since her husband was diagnosed with dementia eight years ago, their relationship became estranged. Mrs. Xu expressed her disappointment about her husband's sibling relationship:

> I have asked his [her husband] siblings to come and talk to their brother. None of them came and visited him, not even a call. When I asked his siblings to come, they blamed my poor care for their brother. I feel they [her husband's siblings] do not have a deep affection in their natal family. I cannot say this to them, nor could they [the siblings] understand [the importance of family affection].

The lack of family affection among siblings is further testified by Mr. Wang (#069), who was taking care of his wife. Realizing that neither children nor siblings were reliable, he completely gave up this fantasy and explained that:

> They haven't contacted us since they knew the diagnosis. I do not expect them to come. What do you want them to do if they come? Will they help? They will not help any way! Even a filial child will not take care of his/her parents in a long term, how can you expect the siblings? If so, why should we have siblings? They are no use any more.

The onset of dementia is a vital factor that estranges the sibling relationship. It can be due to the illness itself since some subtypes of dementia affect communication abilities. However, these cases presented here demonstrate a different rationale: it was the siblings who refused to reach out when family caregivers requested help. Since I had no opportunity to talk to the siblings of dementia sufferers, there was no clear reason about their rejections. My finding underscores the highly dynamic nature of sibling relationships when dementia affects one of siblings. Among the 144 care recipients, only less than ten received some support from their siblings. These care recipients were at early-stage dementia and had maintained independent living abilities. For the above two cases, both caregivers reported that siblings had stopped contacting them since the diagnosis of dementia, even though they all lived in Shanghai. These cases demonstrate the potential exclusion of dementia sufferers by siblings, which deprives their bioecological familiarity.

The exclusion of the kin with dementia from extended family also challenges the bioecological support network based on kinship. Without support from extended families, family caregivers often find themselves in a desperate situation to deal with the overwhelming care burden. On the one hand, they had to fulfill their obligation, regardless of the load of care. On the other, they often felt ambivalent because sometimes they lost their temper during caregiving due to too much work and limited support, as Mrs. Li (#044) did. Mrs. Chao (#W15) also shared with me her point of view about the estranged siblings:

> After my grandparents died, they [her parents' siblings] gradually lost their connections. When my mother got sick and I told her siblings, they showed up once and then never visited us again. We Shanghainese have very shallow family affection. If my parents both die, my brothers and I will take care of ourselves. Then, you completely rely on your children. That's it! Sometimes I yell at my mother, but I have to tell her the reliable of the direct blood relationship. It will not be cut off, even though we yell at her. We have to do all care tasks anyway.

The ambivalent feeling of family caregivers is a testimony to the complexity of resigned familism: family caregivers are neither fully resigned because of the direct blood relationship, nor fully compassionate because of too much workload and limited support.

Given the limited support from extended families could provide, people might wonder why we should care about this relationship if it is not reliable. In addition to create a familiar environment for dementia sufferers, the support from extended families can reinforce the position that an individual possesses within the bioecological niche. However, the onset of dementia and rapid modernization both challenge the availability and sustainability of support from extended families. From a social exchange perspective, the maintenance of extended family relationship needs constantly reevaluation of potential risks and benefits. The onset of dementia interrupts the interaction between the kin with dementia and his/her siblings since it deprives the core element—cognitive abilities—of a person, which reduces one's capability of being a person. Therefore, the previous relationship among extended families need to be reevaluated. Siblings often withdraw from the challenging relationship. The disconnection between dementia sufferers and their siblings also highlights the changing nature of support, from the previous bioecological one within the extended family to the one based on intimate relations among core family members. The previous bioecological support might weaken or disappear along with the progression of dementia, which reinforces solo caregiving phenomenon.

Estranged Adult Children

Changes in intergenerational relationships also contribute to resigned familism. Chapter 4 introduced that the increasing number of older spousal caregivers was accompanied with the disengagement of adult children in eldercare. I also discussed the emerging parent-child relationship as a form of "intimacy at a distance," a concept coined by Rosenmayr and Köckeis (1965). People may argue that the geographical distance reduces the opportunity for senior parents to receive support from adult children, particularly when they need intensive dementia care. This is true but not sufficient. Intimacy between generations could continue despite the geographic distance; however, this distance might also provide an adaptive strategy to avoid intergenerational conflicts (Shi 2017a). If so, family caregivers, particularly senior spousal caregivers, will bear a double burden - the dementia care burden and the relational burden from poor intergenerational relations. The double burden in turn forces spousal caregivers to adopt resigned familism during caregiving.

While acknowledging this relational burden differs from the dementia care burden, in reality, the onset of dementia often intensifies intergenerational conflicts. Sometimes, dementia onset leads to broken family ties. Mrs. Li (#003) exemplifies such a change in parent-adult child relationship. After her husband was diagnosed with dementia, Mrs. Li's relationship with her daughter-in-law changed, and this change in relationship affected her practices of care. According to Mrs. Li, before her husband's diagnosis, she and her daughter-in-law got along very well. Their relationship was more like that of a more and daughter. However, their harmonious relationship turned to hatred after the diagnosis. When Mr. Li was diagnosed with dementia, he stayed in the hospital for several days to receive both physical tests and temporary treatment. After Mr. Li was discharged, Mrs. Li asked the young couple whether she and her husband could stay with them for a couple of days, during which Mr. Li could receive care from the younger generation. Surprisingly, the daughter-in-law refused Mrs. Li because of Mr. Li's dementia. The senior couple has lived alone ever since. Although her son continued to show respect and affection toward his parents, both the diagnosis and the sudden change in the family relationship pressed Mrs. Li to a desperate situation. She told me, "I almost committed suicide." According to Mrs. Li, the apartment of the young couple—large enough (184 m^2) to accommodate the whole family—was originally bought by the senior couple. Ironically, the change of property's ownership from the senior to the young couple, to some extent, stimulated the outbreak of Mr. Li's dementia. Mr. Li opposed transferring the property to the young couple; however, Mrs. Li trusted the young couple and wished to transfer the property to them. The senior couple ended up quarrelling. Eventually, Mrs. Li went behind her husband's back, and the young couple received the housing property. When Mr. Li learned that, his mental symptoms broke out. When the daughter-in-law refused the senior couple's request to stay with her, Mrs. Li said, "My heart was completely broken at that time. I did not know that she is a mean person and just wanted my housing property." Although the senior couple still had their own apartment, Mrs. Li was almost collapsed when she alone had to deal with the dramatic change in the family relationship.

The case of Mrs. Li indicates that, in addition to taking care of dementia sufferers, some family caregivers have to bear the burden derived from intergenerational tension. This tension arises when each generation holds different attitudes regarding the needs of family members. While Mrs. Li trusted the young couple and intended to help them receive the housing property ownership, the daughter-in-law demonstrated an opposing attitude toward the needs of the senior couple. After she gained legal ownership of the housing property, the daughter-in-law seemed unconcerned and even abusive to the needs of the senior couple. Mrs. Li's husband's diagnosis with dementia triggered the intergenerational tension, partly due to the increasing care burden, and partly due to the associated stigma. The intergenerational tension further caused Mrs. Li to resign herself from compassionately taking care of her husband. Her husband's illness constantly reminded Mrs. Li about her poor relationship with her daughter-in-law and her guilt over deceiving her husband and possibly leading to his dementia symptoms. Mrs. Li expressed that she had thought about committing suicide. However, since no one would take care of her husband, she had to live to complete her duty.

The case of Mrs. Li also corresponds to Liu's argument (2017) that, in life practice, intergenerational relationships are a process of continuous negotiation between family members expressing their respective interests and values. He argues that in contemporary China, individuals are no longer living for the continuation of the family or family needs; rather, it is the family structure that constantly changes to fit the needs of individuals. Yan (2011) also points out that traditional norms in contemporary China serve as the "imagination of the community" to shape individual identity, rather than as power resources to constrain an individual to pursue an adequate life. The son's retreat from the intergenerational tension and the daughter-in-law's aggressive behavior demonstrate the discontinuity of traditional family norms. Filial piety will not be valued when there are conflicts between generations, and each has to respond to maximize individual benefits. Mrs. Li was consciously aware of that and decided to give up her expectation of care from her daughter-in-law. However, considering her heartache over their poor relationship, she felt that "it is too hard for me [her] to do that [give up this expectation of care from her daughter-in-law], even though I [she] know[s] I [she] should" The son, who was in the middle of this disagreement, had to balance his responsibility to his nuclear family and that to his natal family. Their family structure has to change accordingly.

Even in families that have achieved a harmonious intergenerational relationship, the onset of dementia and the increasing care burden can break the harmony any time. Mrs. Wang (#068) and her husband stayed with their daughter. Mr. Wang was diagnosed with dementia after brain surgery in 2015. In addition to the daughter, this couple also had a son, who lived nearby. Since her children had work duties, Mrs. Wang took on all care tasks, even though her own health was not well. Recently, Mr. Wang's condition declined so rapidly that he lost his communication abilities and became incontinent. With the increasing care burden, however, Mrs. Wang received little support from her children.

When I asked about her struggles, Mrs. Wang could not hold back her tears as she expressed her disappointment with her children:

> They [the children] do not understand how much I have done for their father. He [my husband] often confuses about the bathroom and kitchen and drinks the water in the bathroom. I have to watch him 24 hours a day. When he soiled the bed, my daughter did not help me clean. Rather, she yelled at me. Recently, she even does not talk to me after work. My son is also short-tempered. I don't think they really care about me. They are worried about their father, and their mother is not important. They think I should do this and that, because I don't have much education. I have suffered too much taking care of my husband, and now I have to bear the pressure from my children. Sometimes, I just want to commit suicide or run away from this family.

This case demonstrates how dementia care interrupts the fabric of everyday family life. The intergenerational tension involves the devaluation of family caregiving. Mrs. Wang said she was not regretful about taking care of her husband. From Mrs. Wang's perspective, caring for her husband not only fulfilled her responsibility, but also liberated her children from work-care conflicts. However, her contributions were not appreciated by her children. They interpreted her devotion as a "natural" choice, and they believed that their father's poor health condition was caused by Mrs. Wang's poor care performance and unwillingness to do caregiving. The conflicts in the Wang family were derived from children's divergent responses toward ill parents: the recognition of their father's needs and the unrecognition of their mother's contributions. Although Mrs.

Wang lamented three distresses (i.e., changes of her relationship with children, her husband's dementia, and her own health condition), her focus was on the parent-child relationship. Being a caregiver whose husband was affected by dementia and an elderly mother whose health condition worsened day by day made Mrs. Wang expect for her children's support and understanding. However, Mrs. Wang's needs were ignored by her children, especially her daughter, who often blamed Mrs. Wang when the father's condition got worse. This situation recalls our opening example, in which Mrs. Gu hanged herself after years of caregiving. Mrs. Wang was trapped into a similar situation: nobody cared about her personal needs or acknowledged her contributions to the family. Without the support from her children, Mrs. Wang resigned herself from compassionately taking care of her husband. According to her statement, she often yelled at her husband when he did not act in concert with her intentions.

The above cases offer us an opportunity to examine the retreat of adult children from engaging in eldercare and how their disengagement affects family caregiving, especially for senior spousal caregivers. The diagnosis of dementia and the increasing care burden often challenge the already delicate intergenerational relationship during modernization. Adult children's estrangement in front of the overwhelming care for dement patients further complicates the family life in Shanghai. The disengagement of adult children, especially their emotional retreat and abusive words, constitutes the primary relational burden when dementia care has already been overwhelming. Consequently, senior caregivers adopt resigned familism when the double burden outweighs their capacity.

Challenges of Marital Relationships

Dementia has a profound impact on marital relationships, in addition to sibling and intergenerational relationships. While all types of illness place distress on a marriage, dementia brings special stresses for marital couples because of the losses that accompany the condition. While some spouses describe caregiving for their partners as a satisfying and rewarding experience (Shavit et al. 2019; Shim et al. 2012; Yu et al. 2018), other spousal caregivers report greater degrees of sadness and loneliness. These spousal caregivers also have more depressive symptoms than non-caregiving spouses (Kim and Schulz 2008; Mausbach et al. 2013). As the disease progresses, the resulting change in the quality of the marital relationship can have a significant impact on spousal caregivers. Scholars have identified challenges of marital relationships in Western societies, including transitional roles, loss of intimacy, and the changing meaning associated with marriage (Davis et al. 2011; Evans and Lee 2014; Harris et al. 2011). These themes have also emerged among participants in my research; however, the context of these challenges and how spousal caregivers interpret and respond to these challenges are different. As with sibling and intergenerational relationships, the intensified marital relationship often causes spousal caregivers to relinquish their familiar roles.

One significant challenge for a marital relationship is the transitional role from being a partner to becoming a caregiver. Along with this transition is the feeling of loss of one's former life, such as personal pleasures, individual time and space, and social networks. If an individual is not prepared for this illness, he or she would feel helplessness and anxiety for the uncertainty of the future. Mrs. Chen (#060) expressed her feelings since she took on the caregiver role:

> When I thought about this disease at night, I often could not sleep. I have given up too much since I started taking care of my husband. Previously, I had so many hobbies: taking photos, making videos, traveling, and opera singing. I used to have many friends, and we would practice together. Now, I have no hobby. My husband and I are completely bundled together.

Her husband's diagnosis of dementia caused a sudden change in Mrs. Chen's life. As a result, she had to change her role in the marital relationship from being a partner to becoming a caregiver. Mrs. Chen's lament of the loss of her private life was a testimony to the challenge of dementia on her marital relationship. Some spouses have prepared for mutual support at the late-life stage, however, the progressive nature of dementia means one's preparation is often inadequate. Mr. Ding (#072) suffered from both dementia and osteoporosis. Recently he had a bone fracture and needed surgery. His wife asked him to stay home when she was visiting the doctor, because it was inconvenient to have him accompany her. But her husband forgot about their agreement and started to quarrel with her when she returned. Mr. Ding claimed that Mrs. Ding had an affair with the doctor, and they were planning to kill him. No matter how Mrs. Ding explained things to him, Mr. Ding intended to report his wife to a policeman. Eventually, this couple met in the police station. Mrs. Ding was so stressed about taking care of her husband, especially about their communication: "I wrote down a note for him, but he did not check; I called him, no answer; and I sent him messages, but, he did not check his phone. It is too tiring to talk to him."

In addition to the loss of the short-term memory that affected his communication, Mr. Ding ended up with a difficult personality. Patients with some types of dementia often act in ways that are very different from their "old" selves, and their personality changes can be extremely hard for family caregivers to deal with. Like the paranoid, Mrs. Ding said that her husband had not demonstrated paranoia like this before in their marriage. Moreover, ever since he was diagnosed with dementia, Mr. Ding became a stingy person. These personality changes challenged the ways Mrs. Ding interpreted about their marriage:

> I feel so depressed to live with him. When he did not like my way of doing things, he would quarrel with me. I do not complain about taking care of him, but what he says and does often makes me angry. I sometimes feel it's meaningless to live with him and want to commit suicide. But, I do not want to place this burden on my daughter if I die.

Due to the lack of appreciation, Mrs. Ding could not find hope in their marriage. She thought her care and devotion was meaningless from her husband's perspective. Rather than completely resigning from caregiving, she continued to care for her husband, which she viewed as a sacrifice for the sake of her daughter. Her great sadness in turn affected her physical condition. In addition to heart disease, Mrs. Ding could not sleep well without taking pills. When she could not sleep, Mrs. Ding recalled her life-long sufferings. When she was young, she was a sent-down youth to a poor and remote village; after she came back to Shanghai, she had to work extremely hard to support her natal family; after being laid off, she studied by herself to enroll in a college for adults so that she could receive a higher degree and be reemployed; and when she was old, she had to take care of her husband who showed little gratitude. Mrs. Ding said, “these difficulties were nothing when I was young. Now that I am old, it’s really hard to continue to deal with difficulties and eat bitterness!”

Marital relationships can get even worse when one partner suffers from dementia. Although it is not uncommon for seniors to get a divorce in Shanghai, a senior couple rarely divorce each other when one is sick. Among the couples I interviewed, there was only one couple who almost pursued a divorce, but the wife decided to take care of her husband for the sake of their children. Previously, Mrs. Zhen and her husband (#071) were sent-down youth and spent most of their time in Jiangxi. After each retired in 2006, Mrs. Zhen decided to go back to her hometown, Shanghai. Her husband, however, wanted to go to his own hometown, Fuzhou, a relatively less developed city. Mrs. Zhen suggested a divorce at that time, because she did not want to go to Fuzhou. The couple had two sons: one in Shanghai and another in Jiangxi. Each decided to stay with one son respectively after their divorce. Before their official divorce, Mrs. Zhen went back to Shanghai. But then, her husband’s health condition started to get worse. He could not sleep at night and had a low mood. The son in Jiangxi recorded a video and sent it to Mrs. Zhen. After watching the video, Mrs. Zhen decided to take her husband to Shanghai for treatment. The result was that Mr. Zhen was diagnosed with dementia. Mrs. Zhen expressed her motivation to take care of her husband:

> If I didn’t take care of him, it would be my son’s responsibility. I do this for the sake of my son! We are a couple just in name only! Anyway, I have done my best to take care of him. I have done this and that for him; not everyone will sacrifice [for his/her partner] like me. I owe him

> nothing. My conscience is clear. He does not know his own suffering, but I am suffering more than him. When he quarreled with me, I really wanted to jump off the eighth floor from my home building. I did not expect that I would have to suffer more late in life.

The meaning of marriage late in life for the Chinese people is more about a moral responsibility than an intimate relationship (Shea 2020). Accordingly, these spousal caregivers' attention has shifted from their lifelong marital relationship to a family responsibility. This responsibility seems to be conjugal support and care, but the aim is for family functionality and to mitigate the potential burden on adult children. In practice, these caregivers engage in resigned familism, and correspondingly, their marital satisfaction is very low.

This unique marital status is often called "Chinese style marriage" by the public, which means the couple chooses not to get a divorce for the sake of their children or their parents, even though he/she is not satisfied with their partner. The onset of dementia intensifies the frustrations in the marital relationship to some extent. Instead of rescuing their marriages, spousal caregivers seek the meaning of life from other aspects. For the above spousal caregivers, Mrs. Chen (#060) often went to a shopping mall to play piano for a while when her husband was sleeping in the afternoon; Mrs. Ding converted to Christianity for spiritual comfort and support; and Mrs. Zhen often joined the community opera program to release her negative emotions. There were also couples who ended up never talking to each other. According to one daughter caregiver, Mrs. Lu (#013), her parents had been always quarrelling with each other after her father was diagnosed with dementia. Her mother could not understand her husband's behavior and often yelled at him. Even after the daughter explained that her father's behavior was caused by the disease, not by himself, her mother still showed a lack of concern toward her father. Similar things happened in the Deng family (#066). According to the daughter, after her father was diagnosed with dementia, her mother's attitude toward her father changed. Unlike other senior couples who always went together for shopping, her mother would rather go by herself. When I asked Mrs. Deng about the sleeping habits of her husband, Mrs. Deng told me that she had no idea about that. She said, "I don't sleep with him. He was sleep-taking, snored loudly, and sometimes kicked me during sleep. I could not stand to sleep together." These sleeping behaviors were symptoms for some types of dementia. Based on my interviews with spousal caregivers, most caregivers chose to sleep with, rather than to separate from their partners, even though they had these disturbances. However, the separate sleeping behavior of spousal caregivers not only indicates their poor marital relationship since dementia onset, but also reveals their endorsement of resigned familism in care practice.

Challenges of Effective Social Support

At a district-level meeting, Mr. Qu, the government official in charge of eldercare in the community where I did my research, expressed his disappointment with the social support for older adults in Shanghai. His parents both died in 2017. As a filial son and a government official, Mr. Qu tried his best to provide good care for his parents. Originally, Mr. Qu thought that after more than twenty years of governmental investment and structural modification since he took on this official role in 1999, social services for elders had improved in Shanghai. However, after five years of intensive care for his own parents, Mr. Qu found that there was limited social support that had reached to families in need. Ironically, he, even with the advantage of being a government official specializing in eldercare, had to purchase all services by himself on the market. Mr. Qu also complained about the uselessness of eldercare services he purchased, "My mother needed respiratory care at home. I bought the service and care equipment from Fushoukang with more than 1,000 RMB [$140 USD].[43] We used the equipment only twice. I eventually threw all of them away because it's useless. What our government has provided to our families is so limited that people could not even feel it (*jiating ganshou budao zhengfu de fuwu* 家庭感受不到政府提供的服务)."

Although Mr. Qu's parents are not dementia sufferers, his experience is equally typical for most Chinese families with elders in need of care. The fact that "people could not even feel it [social eldercare]" indicates the inadequacy and ineffectiveness of social support, which is the main struggle for both families and governments. One the one hand, the Shanghai government has paid much attention to developing a preliminary social eldercare system (see Chapter 3). On the other hand, the message from Mr. Qu and millions of other family caregivers is that these services are far from enough. In respect to economic sufficiency and social advantage, Mr. Qu's parents could have a better chance for more support from social services than other people. However, his parents' story was not a happy one. Therefore, millions of average families may have even less of a chance to receive social support. While it is better to have financial and social advantages to pay for private care or to know what to ask from the system, those advantages will not ensure that families get the kind of care they want, especially for dementia sufferers. It is this

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[43] Fushoukang is a private eldercare company in Shanghai. Its services focus on those elders who are in need of intensive care. It provides both in-home and institutional care.

evenly distributed public concern that drives most family caregivers to become aggressive advocates for elders in need of long-term, good quality care.

In addition to the limited social support for families, Mr. Qu mentioned the mismatch between existing services and the needs of seniors. On the eldercare market, many kinds of services coexisted. The government originally believed that seniors would be able to buy more services on the market with the state's financial support. Thus, the central government introduced long-term care (LTC) insurance in Shanghai and several other cities in China. While acknowledging the good intention of LTC insurance, we should also be cautious about its potential misuse. So far, LTC covers both institutional and in-home care programs. One potential result is that seniors will be funneled to nursing homes because of the concentration of professionals and its administrative advantage. In the long run, in-home care will receive even less attention and fewer resources. In that case, the goal of LTC—to support elders aging in place—will be challenged. Even though LTC covers in-home care, the focus of LTC is to provide professional care rather than daily life support. According to Mr. Qu, however, the priority for elders in need of care is daily life support, rather than professional services. While acknowledging that professional care is necessary, Mr. Qu argues that prioritizing the funding for professional care, which is high-cost, over lower-cost services, such as daily life support, is a waste of social resources:

> The long-term care in Western societies includes both daily life support and professional care, and the purpose of professional care is to enhance the quality of life. But we misuse it in China. On the market, you pay 40 RMB [$5.6 USD] an hour for daily life support, but now, since the

> introduction of LTC, daily life support costs about 65 RMB [$9.1 USD] per hour. Will it be sustainable based on our economic circumstances? No! China is still a developing country! So many elders are in need of daily life support. If this policy can change from the professional-care centered service to life-support service, more elders will be covered. Then, LTC would be sustainable.

As the number of frail seniors continues to grow in China, the pressure to find affordable and sustainable ways of eldercare will mount. The introduction of the LTC insurance is a trial. One key element that affects the practice of LTC in China is the traditional family-based eldercare culture (see Chapter 3). No matter how fancy nursing homes are, most elders want to stay in their own home as long as they can, because a nursing home is viewed as the last resort. Previously, adult children who sent elderly parents to nursing homes were viewed as unfilial, because an elderly person usually had multiple children, and these children should work out ways to support their parents. Due to the One-Child policy, family-based eldercare faces a fundamental challenge, because most senior couples who are currently in their fifties and sixties have only one child, who might not be able to fulfill filial obligations. According to interviews with these senior couples who were also family caregivers, few people would agree to go to nursing homes if they had other options. Given that these couples are relatively young and still taking care of their families, they may change their minds in the future. A combination of in-home care and family-based care may accomplish this goal. Yet, so far, the Chinese state has paid little attention to developing efficient in-home care to support families. Rather, the state continues to emphasize the centrality of family ethics—filial piety—in Chinese culture in general, and the legal obligation of families to support elders in particular. The result is that the overburdened family caregivers adopt resigned familism in eldercare, which will diminish the quality of life for both caregivers and care recipients. When multiple burdens become overloaded for family caregivers, state-society conflicts will occur, as seen in the following statement from Mrs. Niu (#035):

> I have hired two home aides for my father, and I am considering a third one now because both have reported too tired to take care of him. I do not think this issue exists only in my family. Rather, it is a social issue. Why should we families shoulder all care burdens so that none of us can have a normal life? We have two seniors, my father and my father-in-law, and we also have a grandson. My husband takes care of his father. We also have to take care of our grandson, because our son and daughter-in-law have work duties. We do not even have time for a brief respite from caregiving. If I have to appeal to the government, I hope we can solve this social issue together, rather than to place this burden on families.

Zhang (2017a) argues that the state, family, and market realign their shared stake in old-age security and eldercare to give new life to the practice of filial piety in contemporary China. Building upon her thesis, I argue that family caregivers endorse resigned familism, which differs from the value of traditional filial piety, in order to engage in care practice. Mrs. Niu’s case underpins the phenomenon that filial piety remains a central value on the one hand, and the overwhelming care burden challenges the practice of filial piety on the other. Introducing the concept of resigned familism highlights the challenges surrounding family-based eldercare, notably, inadequate social support.

Taking care of dementia sufferers represents a special challenge for both families and society more broadly. So far, many efforts have been made to create dementia-friendly communities in Shanghai. Some nursing homes have started to enroll elders with dementia, and other facilities have also offered dementia care programs in communities. The Shanghai government also aims to create a social environment that is specifically suited to this group of people. Unfortunately, regardless of the quantity or quality of care offered by these facilities, these efforts are insufficient. In 2017, there were about 17,100 social organizations in Shanghai (China Daily 2018). However, based on my work experience and fieldwork, I found that fewer than twenty social organizations specialized in dementia care and support. Although these social organizations attracted a lot of attention from social entrepreneurs and the Shanghai government, their programs could cover only a limited number of dementia sufferers and their families. We should note that the number of dementia sufferers had exceeded 200,000 in 2017 in Shanghai. When LTC initiated trial programs in three districts of Shanghai in 2017, most family caregivers reported that they received little support from the project. Like Mrs. Niu and Mr. Qu, most family caregivers had to seek support from the market. However, since 2018, the LTC project has covered all neighborhoods in Shanghai, there is a possibility to support more family caregivers.

Regarding the quality of dementia care, many eldercare institutions endorse some Western practices by creating special care units for dementia sufferers within their facilities (see Chapter 3). Clustering elders with dementia, however, may create an environment that activates a new burden on dementia sufferers and their families. So far, little evidence has shown that the separation of dementia sufferers from the rest improves their quality of life. The separation is reminiscent of the way we have historically treated mentally ill persons. Without effective supervision, some nursing home aides have a tendency to mistreat elders with dementia (Dong et al. 2008; Wang et al. 2018). One spousal caregiver (#W29) told me that her husband was physically constrained in a nursing home to prevent him from getting lost. The potential mistreatment of elders with dementia in institutions often exacerbates the lack of trust between service providers and family caregivers.

To make sure dementia sufferers (and other seniors who need intensive care) can get better care, some family caregivers have to tip nursing home aides regularly. Unlike some Western societies, tipping is not a common practice in China. The meaning of tipping in nursing homes is at least twofold. First, because family caregivers have limited ability to meet the increasing care demand of patients, they have to tip nursing aides to make sure their kin get better care. Even though some family caregivers clearly know that their kin might not receive good care, tipping demonstrates their expectation. Second, because the payment of nursing home aides is relatively low in China, they have to rely on regular tips as an extra income. Most nursing home managers whom I interviewed clearly stated that they did not require family members to tip aides. However, in reality, many nursing homes had little control over tipping behavior. Family caregivers I interviewed also expressed annoyance with tipping nursing aides. Yet, given the fact that they had to rely on institutional care, family caregivers had to accept the unwritten rule in some nursing homes and tip nursing aides there. "If not, you do not know how these nursing aides will treat them," said Mr. Tang (#W28). In some nursing homes, gifts or gift cards are useless; families have to give a regular tip or bonus in the form of cash—anywhere from 200

RMB [$28 USD] up to the equivalent of the aide's weekly salary, depending on the degree of care intensity. For instance, Mr. Tang and Mrs. Hong (#017) tipped 200 RMB [$28 USD] per month, whereas Mrs. Jiang (#W29) and Mr. Xue (#W17) had to tip 500 RMB [$70 USD] and 400 RMB [$56 USD] per month respectively because other family caregivers had already given such a large amount of money. In addition to the tips, some family caregivers have to buy extra food for nursing aides to ensure they will treat their kin properly. Although not all nursing homes allow tipping behavior to disturb their administration, the nature of tipping—from an expression of gratitude to a requisite for care—indicates the chaos of eldercare market in Shanghai.

Another characteristic of the eldercare market is the stratification of services. Like elsewhere, there is a hierarchy of eldercare services in Shanghai, ranging from the upper-level, personalized services to the lower rank nursing homes. While some privileged seniors who are economically sufficient can afford upper-level services, the majority of elders living in Shanghai have to choose from average mediocre nursing homes based on their affordability. Due to the relatively poor infrastructure, nursing homes at the lower levels of the hierarchy have to charge less for their services, which in turn deprives their opportunity to improve their competitiveness. In order to survive on the market, these nursing homes have to hire less qualified nursing aides at a lower salary than those in upper-level nursing homes. The relatively low salary drives these nursing aides to seek extra income, i.e., tips from families. The preliminary eldercare system in Shanghai, to some extent, does not relieve the burden on families. Without effective supervision, dementia care is transformed from a physical burden to a financial one, which many families in a lower economic bracket cannot afford.

Among those who are financially disadvantaged in Shanghai, one group of people is worthy of special attention—the former sent-down youth who returned to Shanghai after their retirement. The sent-down youth, or "educated" youth, also known as the *zhiqing*, were a group of young people who left their urban hometowns and worked in rural areas from 1950s to the end of the Cultural Revolution. Since 1977, the sent-down youth have gradually returned to their hometowns via various ways (Gold 1980). Some sent-down youth were not eligible to return immediately because they were married locally. This group of people had to wait until they retired, after which they applied for the return to their hometowns. However, after the sent-down youth returned to Shanghai, they faced a dilemma. Two significant portions of their social security insurance were less than expected: their retirement pension was less than what Shanghai residents received, and their health insurance was restricted from certain aspects. China's social security law is promulgated by the central government, but its administration and specific details are governed by local authorities. In other words, an individual's pension and healthcare benefits depends on where he/she retires. For example, if one retires in Guizhou before returning to Shanghai, then his/her pension is distributed by Guizhou Province. Similarly, his/her health insurance is subject to the policy in Guizhou Province, rather than that in Shanghai. This regional disparity of social security insurance places many seniors who were former sent-down youth into a disadvantaged situation, because the average pension in Shanghai is much higher than that in other remote areas. However, for various reasons, these seniors also have to shoulder eldercare responsibilities. Therefore, the former sent-down youth suffer from both a physical care burden and a financial burden in Shanghai.

Because of the financial burden, family caregivers who used to be sent-down youth are more likely to endorse resigned familism during caregiving. Mrs. Chen (#049) used to be a sent-down youth in Jiangxi. Due to her long-term caregiving, Mrs. Chen suffered from a slipped disc and lower back pain. The doctor suggested surgery. However, due to her limited pension and the restriction on her healthcare insurance in Shanghai, Mrs. Chen could not afford the high cost of surgery. According to her daughter, they had to pay for the procedure entirely of pocket, and then apply for the reimbursement in Jiangxi. This process was much more complicated than it sounded:

> They [the government officials in Jiangxi] have to validate whether you are alive each year. The Community Service Center has to provide a [certificate of] proof, and then you mail it to Jiangxi. If not, they will not provide service to you. It's extremely cruel for my mother to live in this world.

Because of the structural barrier, Mrs. Chen could not afford the surgery, and her poor health condition did not allow her to fully devote time to take care of her husband. Similarly, Mr. Gan (#082) could not afford the surgery for his gallstones, which sometimes caused severe pain. Even given his poor health, Mr. Gan was the only person taking care of his mother due to conflicts with his brother. In our conversation, I could feel his severe depression and sense of hopelessness of life. No matter how hard I tried to help, he expressed that, "My life is worthless. If my disease is a mild one, then, it is meaningful to seek treatment from the clinic [because of the instant reimbursement]. If it is incurable, then it's my fate to die." In addition to his depression, he lamented life difficulties for his family to live in Shanghai:

> My wife stays with my daughter and helps by grandparenting. I stay with my mother and take care of her. We do not even have a living place for our own family. My pension is about 2500 RMB [$350 USD], and my wife's is about 3000 RMB [$520 USD]. Our pensions together are equal to that of my brother in Shanghai. Even though we are Shanghainese, we do not have equal rights [with other people]. Instead, we only have the obligation to take care of our parents. My brother can afford a pair of a-thousand-RMB shoes, but I cannot. I can only buy shoes than cost less than a hundred RMB.

The two stories above demonstrate the disparity of the national social security system and healthcare system in urban China, i.e., the regional difference of social benefits. The former sent-down youth--who responded to the nation's calling to contribute to the economy in remote areas during the Mao era and who returned to their hometowns late in life--are treated differently from other Shanghainese. Based on their narratives, the primary burden is not about taking care of their families; rather, it is the ambivalent feeling of being Shanghainese while being excluded from social benefits that causes the crucial challenge for their daily life. They cannot have an equal access in terms of healthcare. Ironically, they have to validate their "living" status every year to their former work units to maintain their pension accounts and receive their healthcare reimbursement. These structural disparities further prevent them from fully devoting time to taking care of themselves and their family members. Because of these disparities and the sense of hopelessness to make a change, family caregivers who used to be sent-down youth endorsed resigned familism. As Mr. Gan said, "We have no status at home, but rather take care of elders first." Being family caregivers whose contributions are neither valued by society nor by their family members challenges their philosophy of life. Even less often do they negotiate with or resist the local government. Having such discussions can only open old wounds and raise long-buried issues without any practical help.

Conclusion

This chapter contextualizes the practice of resigned familism and examines its social causes in Shanghai. Family caregivers who adopt resigned familism do not feel fully resigned to caregiving, nor fully compassionate toward their family members. Local idioms such as *wang si wang* demonstrate the practice of resigned familism. Folk understandings of dementia (e.g., *tianshu* and *baoying*) further complicate the practice of resigned familism. Terms used to describe dementia such as *laonian chidai* and derogatory names for memory clinics also activate stigma, which in turn facilitates the endorsement of resigned familism.

Social factors that indirectly contribute to resigned familism include family estrangement and a lack of effective social support. Rapid modernization together with dementia-related stigma facilitates the division of extended family, which erodes the bioecological support network for dementia sufferers. The maintenance of the sibling, parent-child, and marital relationships, to some extent, is challenged by the onset of dementia and the increasing care burden. During this process, family caregivers not only experience the loss of a bioecological support network based on kinship, but also the increase of care burden on themselves. When these caregivers cannot deal with the overwhelming care burden alone, they turn to resigned familism. Similarly, due to limited and ineffective social support, family caregivers who are in better economic circumstances seek market-based eldercare, whereas those in a poor condition have to bear the burden by themselves. Regardless of their economic conditions, all family caregivers encounter the poor quality of social eldercare, and each has to figure out individual strategies to access better care from the market. Without effective domestic and social support, family caregivers endorse resign familism to deal with their care burden. By examining the power structure that causes resigned familism, this chapter lays out the burden discourse of family dementia caregiving in Shanghai.

Chapter 7 Transitions of Care and Transformations of Relationships

Mrs. Hu, aged 83, was an ophthalmologist, and her husband, aged 87, was a navy veteran. Mr. Hu was diagnosed with dementia around 2003 and since then, Mrs. Hu became the primary caregiver. This couple enrolled in a senior center specialized in dementia care in 2010 when Mrs. Hu could not shoulder the care burden by herself. This program became ineffective when Mr. Hu's condition worsened in 2013. Mrs. Hu originally did not want to send her husband to a nursing home if her three children could help. However, their oldest daughter—who received little education during the Cultural Revolution, later became a factory worker, and then was laid off in her early forties—was diagnosed with depression several years ago. Although their only son lived nearby, he was jobless throughout his whole life and also developed alcoholism. The youngest daughter, who had both higher education and a better job, was unavailable because she married an American and moved to the US. Rather than receiving help and support from the three children, the Hu couple had to rely upon themselves. Sometimes, they had to financially support the two children in Shanghai. Mrs. Hu, after realizing that she could not bear the burden anymore, eventually sent her husband to a nursing home in November 2013. After that, she continued visiting her husband every other day to make sure he could adapt to the new environment. The sad news was that, one night in March 2014, Mrs. Hu passed away without family around. She was found two days later by the Resident Committee. A month later, her husband also died without family around in the nursing home. When discussing their death, neighborhood residents always said Mrs. Hu had a "good" death because she passed away so "peacefully" and "without too much pain" for herself and her families. Her husband, however, had a "poor" death because of his dementia conditions.

The vignette highlights two themes surrounding dementia care: (1) transitions of care when primary family caregivers could not bear the increasing care burden; and (2) transformations of relationships between caregivers and dementia sufferers along with transitions of care. By identifying these themes, I intend to examine interactions between primary caregivers and other family members and between domestic care and social support. I pay attention to how these interactions relate to local constructions of the personhood of dementia sufferers, explorations of the meanings of life and care, and the contextualization of "good" death.[44] In this chapter, I look at family caregiving as an ongoing, dynamic, and unfolding experience that constantly interacts with social environment. Findings suggest that family caregivers reflexively use resources provided by domestic settings or institutions to reframe their relationships with dementia sufferers. Moreover, along with the progression of illness, family caregivers reconstruct the personhood of dementia sufferers and recreate meaningful ways of life and death. Thus, an analysis of dementia care requires taking into account the trajectories of care, the social environment that family caregivers frequently interact with, and the transformative process in which identities, relations, and meanings of life and death are recreated (Long and Campbell 2020).

Transitions of Dementia Care

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[44] I use quotation marks to highlight the notions of good are from informants.

Similar to the long-term care system in the U.S. (Kane and West 2005), transitions from family-based care to assistive care and finally to institutional care constitute the trajectory pattern of dementia care in Shanghai. These transitions occur because of the increasing care demand or the poor health conditions of family caregivers. Among the 144 dementia sufferers, 65 were cared for only by spouses, 26 only by adult-child caregivers, nine taking care of themselves, seven institutionalized, and the remaining 37 cases ended up with a mixed care (see Table 3 in Chapter 4).

Mixed care refers to multiple caregivers involved in care practices. It often includes a primary and a secondary caregiver. Sometimes, a third caregiver is needed. Primary caregivers are often spouses or adult children; secondary caregivers can be either adult children or home aides. From the above statistics, we can see that dementia care is often organized within domestic settings, rather than institutions. In other words, a large portion of the care trajectory—from solo- to mixed caregiving—takes place within domestic settings. For those who were institutionalized, they also experienced these domestic care trajectories (see discussions in later sections). This is partly due to the traditional culture that emphasizes family-based care, and partly due to the underdeveloped social services. In China, transitions of care entail: whether another family member could get involved; whether hiring a home aide to continue family caregiving is possible; and whether institutional care is a desirable option for both family caregivers and dementia sufferers. Examining rationales of choosing or rejecting a specific care pattern is significant since they directly reflect interactions between family and society.

From solo- to mixed- family caregiving

The transition from solo- to mixed- family caregiving is closely related to the availability of family support. Among the 37 mixed-care cases, twenty-two families had multiple family caregivers, with fifteen cases having adult children as secondary caregivers and seven cases having siblings as secondary caregivers. Their caregiving time ranged from six months to more than ten years. The involvement of adult children in care occurs when health conditions of parents—either caregivers or dementia sufferers—get worse, or after the death of one parent. For these adult children who were secondary caregivers, half lived with or nearby their parents and shared care tasks with primary caregivers; and the rest lived very far and had to travel for a long distance. Here I look at the emergence of mixed family caregiving as interactions in which care settings and tasks reflexively constitute each other. That is, care tasks are often shared with the most proximate family member, who is often living with the primary caregiver. For instance, a critical condition that requires family members to share care work is cross-gender caregiving. Although some adult children have "normalized" personal care for a cross-gender parent by referring to similar care previously received (e.g., by comparing it to the care of a mother for her baby), there are still cases that consider it as a taboo:

> My mother lives with my brother. He is in charge of my mother's food and drinks. My brother does not want to do bathing, dressing, and toileting because of modesty. I also feel it is inappropriate for him to do personal care since my mother has two daughters. I take charge of my mother's personal care from Monday to Friday, my sister does that on the weekend, and my brother is in charge of other aspects of care. Thus, we all have some time to rest. (#037)

While personal care is often performed by spousal caregivers as a way of expressing love, it becomes a challenge for an adult-child caregiver who is opposite-gender for widowed, senior parents. If an adult-child caregiver cannot handle the “negative” association of cross-gender caregiving, he/she will turn to siblings for help, as the above case indicates. Yet, not every adult-child caregiver is able to find an opposite-gender sibling who would like to take personal care on behalf. Occasionally, the shared work is conducted by the spouse of an adult-child caregiver:

> My father stays with me. I take charge all other aspects of care except bathing, dressing, and toileting. I ask my husband to help these personal care tasks. He originally did not know how to do these things. After I showed him, he was willing to help. People say it’s OK to do cross-gender care tasks, however, I still feel it is awkward. He is a man, and I cannot overcome the psychological barriers. (#025)

Cross-gender caregiving is made possible by sharing care tasks with other family members. Personal care such as bathing, dressing and toileting are just part of caregiving tasks; there are also physical care (e.g., cleaning, cooking, laundering, shopping, and running errands), practical care (e.g., visiting doctors, providing transportation, and managing finance), and emotional care. When all of these care tasks overload an individual caregiver, shared care work is needed.

Equally worth attentioning is that family serves as a social space in which interactions—between primary caregivers and other family members—are intended to fulfill care obligations and to accomplish economic and social activities. The case of Yuan (#024) demonstrates how family members adjust to solve the care-work conflicts. Mrs. Yuan was diagnosed with dementia in Oct 2016 at the age of 77. She was originally cared by her husband. Her conditions rapidly declined after a fall in Dec 2016. Since then, Mrs. Yuan constantly fell down and she completely lost continence in Feb 2017. The increasing care burden challenged Mr. Yuan's ability to provide care. As a result, Mr. Yuan was hospitalized due to a heart attack. The Yuan couple had two daughters. These two daughters together ran a supermarket in East Shanghai, which was their primary financial resource. Considering that the senior parents were both in need of care and her daughter was going to give birth, the elder sister voluntarily resigned her job and shouldered the family responsibility for both eldercare and child care. In order to maintain the supermarket, the elder sister asked her husband to quit his job so that he could replace her position to maintain a stable financial income. These rapid care reconfigurations, however, did not completely solve the work-care conflicts. Mrs. Yuan, the daughter caregiver, aged 52, expressed that:

> I could not sleep thinking about my whole family. My mother needs intensive care during the day; my father can help a little bit, but his health conditions are not good after the heart surgery; and my daughter and her baby also need a lot of care after she gave birth. What I have done every day is to fulfill their needs; I don't even have time to think about myself. (#024)

Yuan's case indicates that Chinese family is centered on economy, and all other activities, such as care obligations, are important but should be peripheral. Additional caregivers are needed only when solo caregiving would not be appropriate to satisfy all the needs for both patients and primary caregivers. If not, solo caregiving implies high costs for both of them, e.g., negative interferences in their health, and therefore, more economic loss for the whole family. The economy-oriented ideology also compels family members to sacrifice themselves—such as private time and reconfiguring one's position in the family—to reduce the negative impacts of work-care conflicts. Most family caregivers who were born in the 1960s or before would not complain about their personal sacrifice because they were fully aware of the importance of maintaining a living.

In any case, family caregivers have the option of resorting to other kinds of care such as home aides, but this does not happen for the following three interrelated reasons. First, some dementia sufferers or caregivers opposed the idea of hiring a home aide due to concerns about money and an ideal of self-reliance, which in turn reinforces the economy-oriented family ideology. Mrs. Hua (#W21) had taken care of her husband for more than ten years. Her three children offered to hire a home aide for her but Mrs. Hua declined. Hua said, "I am not an aristocrat, and I have my pension. I rely on myself. If I cannot do care anymore, just let it go. If there is an aide doing everything for me in my home, I cannot watch myself being lazy. I also do not want to spend money in this way. "

Second, some family caregivers argue that family should be the primary caregivers for older people. Resorting to other modes of care such as home aides or nursing homes should be considered only when the whole family is unable to provide all care tasks. For example, Mr. Gu (#048) took care of his wife and both were in their eighties. Despite their high pension that could afford them to move to a nursing home, Mr. Gu insisted on family-based care. He was in charge of the care organization and assigned care tasks to each child: his daughter in charge of the personal care, the younger son for food and drinks, and the older son for medications. Mr. Gu explained why he did not want to hire home aides or move to a nursing home: “We have three children and they can share the care tasks accordingly. If there is only one child, then the burden is too much. I will think about hiring a home aide if care burden is too much someday. But so far, we are able to deal with it.”

Third, some caregivers have a negative impression of nursing homes and the overall quality of care provided by home aides in the market. This impression derives from media reports, personal experiences, or acquaintances’ experiences. So they believe that the care they provide is better than that of other care providers. For example, Mrs. Yu (#098), the daughter caregiver, expressed that she would not send her father to a nursing home because of the poor quality of care reported by the media. People who sent their senior family members to nursing homes also expressed their negative attitudes toward institutional care such as lack of freedom or the potential need to bribe nursing aides. Similarly, Mrs. Wang (#079), based on her personal experience, also felt that home aides were “money-oriented,” they would not provide care “from the heart.” Without a trust of market-based care, family caregivers have to rely on themselves to shoulder the burden, even though it might be overwhelming in some cases.

Although there is a decline of family support for elders during China’s modernization, family remains the backbone of eldercare. It represents the largest single source of care for older adults. In all societies, family needs to coordinate care with other social and economic activities to sustain the daily life, in accordance with situation-specific reconfigurations. This involves intricate ordering, coordination, and distribution of care tasks and other family activities within domestic settings. In examining the complexity of domestic care, John Law (2010) proposed the concept “care as choreography” to examine the care-killing tensions in veterinary practice in Britain. Similarly, Goodwin and Cekaite (2018) analyzed embodied family choreography through examining the relationship among care, control, and mundane creativity within the time-space dimension. The metaphor of choreography reminds us of the effort that goes into family: what may sometimes appear simple from the outside is never that way in practice. Given the context of dementia care, efforts include the gender appropriate care tasks, the balance of care obligation and family as an economic unit, and the negotiation of family-based care and market-based care. Reconfiguring family structures to some extent can solve these conflicts; however, when efforts fail, family caregivers have to seek alternatives.

From family caregiving to seeking in-home help

The transition from family caregiving to seeking in-home help occurs because it is not possible to maintain a previous family care arrangement, regardless of solo- or mixed-family caregiving. The impossibility is often related to three main concerns. The first condition that forces adult children to seek market-based solution is the ambivalence of cross-gender caregiving for personal issues. When seniors begin to need intimate care but refuse to receive it from oppose-sex children due to modesty, and there are no other relatives available or willing to provide it, adult-child caregivers have to turn to formal market. The issue of modesty and its role in promoting people to seek other care providers outside the family is illustrated in the account of Mrs. Niu (#035). Mrs. Niu’s father was 93 years old and needed personal care. Despite his cognitive impairment, he refused his daughter to bathe him due to the modesty, no matter how Mrs. Niu explained that she did not mind the cross-gender caregiving. The result was that Mrs. Niu had to hire a home aide to deal with her father’s personal care.

The second condition is when the family is unable to handle new demands in terms of both time and energy. Here is the testimony of a husband caregiver, Mr. Yu (#W33), who tried solo caregiving first, but failed due to his bone fracture. During his stay in the hospital for about ten days, he turned to his daughter for help to take care of Mrs. Yu. After Mr. Yu was discharged, his health condition did not allow him to continue solo caregiving. In order to continue home-based caregiving, he hired an aide to help. When I asked why his daughter did not provide support, Mr. Yu said, “She is a high school director and very busy with school work. I cannot give her too much burden. Now, the aide helps me three hours every day for cooking and doing laundry. It’s enough.”

The increasing care demand offers an opportunity to examine the intergenerational relationship during care transitions. On the one hand, adult children’s responses toward the burden directly reflect their relationships with senior parents. In the above case, the daughter of the Yu couple did not financially support her parents, nor did she regularly visit them. She only did so in emergency situations. This was because the Yu couple was a remarried couple and the daughter was their only biological child. Considering that Mrs. Yu also had a son who never showed up, the daughter might not be willing to take the full responsibility. In another case, the daughter of the Kang couple (#063), who was their only child, financially supported her parents when her mother could not continue solo caregiving. Mr. Kang had severe dementia and his wife who took care of him also developed a list of chronic illnesses. Mrs. Kang wanted to send her husband to a nursing home. Their daughter, however, felt morally guilty if her father was institutionalized. Due to her work-care conflicts, the daughter hired two home aides to help her mother continue home-based care. Mrs. Kang said, “My daughter is extremely busy with her work. She hired two nursing aides for us, one in the morning, and the other in the afternoon. Together it costs her about 5,000 RMB [$700 USD] a month."

On the other hand, while acknowledging that senior parents indeed need adult children's support to deal with the increasing care burden, this does not mean that they are willing to accept it always. This paradoxical condition is evident by the Guo couple (#W10), who are in their eighties. Mrs. Guo was diagnosed with vascular dementia and also paralyzed after a severe stroke. Mr. Guo, unfortunately, had a permanent hand injury in which he lost three fingures several decades ago. In many aspects, this couple needed care and support. Their two children were also willing to help. However, according to Mr. Guo, who expressed a deep guilt of placing too much burden on their children:

> My son and my daughter asked us to stay with them last year since cooking was a challenge for us. We had rotated each child for a year. My son and daughter-in-law are both at work, and my daughter has retired but she needs to take care of her father-in-law who also has dementia. When we stayed with them, I felt we were an additional burden to them. They don't say anything about us, but we can sense [*shixiang*] their hardships. I decided to move back to our own home last month. If they are willing to come, they can visit us and help us buy something. Now, we depend on the meal program provided by our government.

The Guo couple demonstrates another intricate relationship with their adult children. This is characterized by senior parents' partial relinquishment of adult-child care, considering their children's care/work duties. This paradoxical situation is captured by Mr. Guo's remarks of "to sense their hardships," even though their children are willing to provide care. “To sense” or *shixiang* in Chinese means one’s moral obligation of not bringing additional interruptions or burdens to those who are already in difficulties. It is within this moral discourse that one has to seek social support even though he/she might prefer child care. This complex care configuration illustrates how family caregivers navigate support between home-based care and community resources, and how to maintain a harmonious relationship with the younger generation.

The third concern of turning to in-home help is to avoid or postpone institutionalization of dementia sufferers. Widowed elders with dementia primarily rely upon their adult children. Rather than assuming all care tasks, adult-child caregivers often seek help from the market. Unlike those who send seniors to nursing homes, these adult children achieve a balance between caregiving and private issues through seeking social services. For example, Mrs. Gao (#W08) and her three siblings had taken turns to care for their mother for more than ten years. Originally they thought they could handle the burden because they were all retired. After more than ten years of caregiving, they were unable to continue to do so because each had private family issues: two siblings were going to take care of their grandchildren; Mrs. Gao had to take care of her husband who was diagnosed with lung cancer; and the other sister had to travel to Japan to help her daughter’s business. Because of the distrust of institutional care, they decided to hire a home aide to help caregiving so that they were able to continue the original rotating care. When I asked Mrs. Gao about the financial burden of hiring a home aide, she said, “My mother’s pension is to pay the salary of the home aide, and each of us contributes 500 RMB [$70 USD] per month for other daily necessities, including medications, diapers, food, and drinks.”

Equally worth mentioning is that seeking in-home help does not mean that family caregivers embrace the market-based eldercare; instead, in-home help is a strategic adjustment of continuing the previous care arrangement. Due to the poor reputation of nursing aides, family caregivers have generated a list of strategies to supervise home aides to avoid elder mistreatment. For example, Mrs. Wang (#100) installed a home camera to monitor care practices of the home aide, and Mrs. Li (#051) assigned only less professional care tasks such as house-keeping to the home aide, and kept the most important care tasks such as emotional care and medication to herself. Because of the distrust, home aides play a secondary role in mixed care. As I will discuss in the following section, this distrust extends to institutional settings. When families or dementia sufferers oppose the idea of nursing home care, home-aide care becomes a solution to deal with the overwhelming care burden.

From family-based care to institutional care

Most families can deal with the increasing care burden by reconfiguring care arrangements. However, some families have to turn to institutional care when it is not possible to maintain family-based care. During my fieldwork in 2017, only seven families sent their kin to nursing homes, and another two families sent their parents to nursing homes one year after my research. The decision-making process reveals not only the nature of family relationships, but also the relationships between family caregiving and institutional care.

Dementia sufferers' preferences for certain types of care are especially important to facilitate the decision-making process. When patients had expressed their opinions to nursing homes before developing dementia, the decision-making process is much easier for family caregivers. For instance, Mr. Wu's (#W17) mother told her four children that she would like to go to a nursing home when someday she required intensive care. After Wu's mother was diagnosed with dementia, her four children took turns to care for her. But they could not handle the increasing care demand after their mother lost continence. Because of the clear statement of their mother, it facilitated them to make a final decision to send her to a nursing home.

The decision-making process is more challenging for families of advanced dementia sufferers who did not express their opinions. This is partly due to the emotional and value-laden choice that must be made, and partly due to the need for surrogate decision-making. The Zhang family (#W01) exemplifies these challenges. Before Zhang's mother was sent into a nursing home, she was cared by three daughters and a home aide. After a severe bone fracture, she was paralyzed and the following surgery even worsened her dementia conditions: Zhang's mother completely lost her ability to recognize her family members. What made things more complex was the mother's diabetes that often sent her into a coma. Sometimes she lost her continence, which was beyond the ability of family caregivers. As a result, the three daughters had to reevaluate whether family-based care was still reliable for their mother's conditions. They started to search for a suitable nursing home for better care. According to Mrs. Zhang, they found two nursing homes: one was the municipal nursing home specialized in dementia care, which provided professional care but was very far from their homes; and the other was a community-based nursing home, which provided necessary hospital care and was very close to the three daughters' living places. Even though the community-based nursing home seemed a desirable choice, it took a lot of time for the three daughters to make the decision because of their emotional attachment to the mother:

> We all love our mother and want to take more care of her. But her dementia conditions do not allow us to do that. We were also worried about her bed sores after she was bedridden, but none of us had professional care experiences. Moreover, when my mother was in a coma, we had to call 120 [emergency care in China] each time. Eventually, we decided to send our mother to the community-based nursing home.

After sending the mother to the nursing home, Mrs. Zhang and her two sisters took turns to visit her mother to make sure she received good care. After learning that sedative drugs might worsen dementia conditions, they communicated with the physician there to make sure that their mother would not receive these drugs. The most positive change of her mother was that, according to Mrs. Zhang, “Her health condition became better and better. She had no bed sores and also gained some weight. Indeed, professional care has helped a lot for both reducing our care burden and improving the quality of life of our mother.”

The Zhang case reveals that the decision-making process consists of four interrelated steps: identifying needs; exploring choices in the market; making an information-based decision; and reevaluating the institutional care performance. The first step calls for the evaluation of dementia sufferers’ physical and cognitive abilities, the capacity of family-based care, and the professional care they need. For most family caregivers I interviewed, they were fully aware that they could not handle the increasing care demands from patients. However, not many family caregivers had a clear understanding of the professional care they needed. Due to the lack of accurate information and the misrepresentation of institutional care in the media, they were often worried about potential mistreatment in nursing homes. Considering public stigma, some family caregivers also believed that nursing homes did not enroll dementia sufferers. Their concerns demonstrate the distrust of nursing homes. From some family caregivers' perspective, family caregiving is always better than institutional care. For instance, Mr. Zha (#054) had taken care of his mother for more than ten years. During our interviews, I learned that his mother needed professional care due to her aggressive behavior and her refusal to eat and drink. Mr. Zha was also overwhelmed by these challenges. I suggested that he could send his mother to a nursing home for professional care so that he could take a respite. Surprisingly, he rejected my suggestion and argued that, "Nursing homes do not enroll these elders. She [my mother] is always screaming and yelling at strangers. If I cannot take care of her, I do not think they can deal with her."

The distrust toward nursing homes is further testified by seniors' rejection of being institutionalized. For most seniors, nursing homes are not professional institutions; rather, they are "curses for elders" that they should try to avoid. This notion is not uncommon in Shanghai where many seniors swear that they will not go to nursing homes late in life. Tensions and conflicts often occur when family caregivers cannot deal with the increasing care burden. For example, Mrs. Niu (#035) suggested her father go to a nursing home after their previous home aide quit her job. No matter how hard Mrs. Niu tried, her father always said "no" to nursing homes:

> I begged him to go to a special institution for upper level cadres. He immediately said "no." I deceived him that we were going to have a

> vacation, where there was massage and rehabilitation therapy. His answer remained “no.” He is confused for other things, but he has a clear mind on nursing homes. For him, nursing homes are for those abandoned by their children. So, he doesn’t want to go.

Because of the distrust toward social services, elders or their family caregivers reject institutional care. As I discussed in Chapter 3, this distrust, on the one hand, often places too much burden on family caregivers; and on the other, it hinders the further development of eldercare services in China. In reality, some families will send their kin to nursing homes when they cannot bear the burden any more or dementia sufferers have lost their cognitive abilities. In such conditions, family caregivers will make a surrogate decision. If the spouse survives, it is the spouse’s responsibility to make the decision; if not, adult children make a decision together. For example, Mrs. Hong (#017) decided to send her husband to a nursing home because she could not deal with the increasing care burden, and her two sons did not provide support. Similarly, in order to prevent their father from getting lost and being cheated, Mr. Li (#095) and his sister decided together to send their father to a nursing home.

Once families have an appropriate evaluation of dementia sufferers’ needs and the inadequacy of family-based care, they then begin to search available nursing homes in order to make an information-based decision. Elements that are often taken into consideration include the location of nursing homes, access to public transportation, charges of institutional care, and accommodation of dementia sufferers. Although the Shanghai Civil Affairs website provides the contact information of local nursing homes, not all nursing home have their own websites to provide more details. Therefore, family caregivers and other members have to travel one by one to find the most appropriate nursing home. Occasionally, these families refer to the experiences of their neighbors or acquaintances, which saves a lot of time and efforts. Mrs. Jiang and her daughter (#W29) together sent Mr. Jiang to a nursing home because they had a special relationship with a physician there, even though it was far from their home. This case demonstrates that the accuracy of information and the trust relationship played a significant role in decision-making.

After searching several nursing homes, families will decide which one is the most appropriate. The decision of a certain type of nursing homes equally reflects their values and concerns about institutional care. Some family caregivers take locations and charges as primary concerns since they want to assist with care and maintain a close relationship with their kin, even after they have been institutionalized. For instance, Mrs. Hong (#017) chose a nursing home near her neighborhood so that she could visit her husband every day; Mr. Xue (#W17) and his three siblings had to take the cost of a nursing home into consideration because their mother did not have enough savings for institutional care; and Mr. Zhang (#101) successfully found an ideal nursing home for his mother, which was close to their living place and had a relatively lower cost.

While economic circumstances of dementia sufferers and locations of nursing homes are primary concerns for some family caregivers, the professionalism of institutional care is more significant for others. For these caregivers, their decision-making is patient-centered. When family caregivers cannot afford a nearby and costly professional care facility, they have to give up their location preference and choose distant nursing homes. For example, Mrs. Liu (#050) chose a nursing home that specialized in dementia care in

Jiading District, which was located on the outskirts of town. It often took about two hours for her to travel by subway. She made that decision because of the professional services:

> The nursing home has doctors, nurses, and nursing aides. Doctors check patients twice every day and sometimes they provide on physical examination. This part of services costs about more than 1,000 RMB [$140 USD] per month (after reimbursement). I also hired a male nursing aide to help with personal care. Each day, the nursing aide will take my husband to acupuncture and rehabilitation. He takes much better care than I did. So, I pay about 8,000 RMB [$1120 USD] for the nursing aide. If adding other costs, it will be more than 10,000 RMB [$1400 USD] per month.

The last step of the decision-making process is to reevaluate institutional care performance. This step is important because of the lack of trust toward nursing homes. If dementia sufferers are mistreated by institutions, family caregivers have to take further action to negotiate the care they purchased or directly move patients out. For example, after Mr. Xue (#W17) sent his mother to a nursing home, he and his three siblings took turns to visit their mother every day. Their regular visits were to prevent potential mistreatment. Even so, Mr. Xue was not sure whether his mother was mistreated when they were absent. When I asked him "what mistreatment means," he gave me the following case:

> My mother stayed with four elders in her room, and there was only one nursing aide in charge of them. One day, I saw that a senior soiled the bed, but the nursing aide did not clean her immediately. The whole room

> became smelly. It’s not only about the smell, but also the potential for infection. After I saw that, I felt the nursing aide was not professional.

The gap between family caregiving and institutional care in terms of quality of care—such as attitudes toward the needs of elders—explains seniors’ fear of nursing homes in China. The poor quality of care is also evident in the aspects of losing one’s freedom and dignity after being institutionalized. Mr. Tang (#W28) sent his mother to a nursing home due to his work/care conflicts. Before his mother was institutionalized, she could walk and communicate. Shortly after a month, when Mr. Tang visited his mother, she could not walk. Nor did she recognize her son. Mr. Tang found that, in order to manage toileting, nursing aides asked all seniors to sit on the toilet seats after breakfast. According to Mr. Tang, “All their care tasks are centered on *chi he la sa* [eating, drinking, defecating, and peeing]. Many seniors who could use the toilet were forced to use toilet seats in a public space. I asked them why they did not allow seniors to use the toilet in private. They told me that they did not want elders to fall down.” After a month, Mr. Tang moved his mother to another nursing home due to the extremely poor quality of care.

Overall, transitions from solo family caregiving to institutional care all point to the increasing care demands and limited social support for family caregivers. In many aspects, a family has to reconfigure care organizations to meet demands. Care reconfigurations within domestic settings demonstrate not only the changing context of caregiving, but also the intricate relationship between primary caregivers and other family members. In many cases, the function of families is economic-centered, and care organization has to be subordinated to this goal. In-home help and institutional care serve as strategies for family caregivers to deal with the increasing care challenges. The lack of trust between family caregivers and social service providers underpins the poor relationship between family and society. While acknowledging that poor quality of care exists only in some public nursing homes and most private and hybrid ones have improved their services, the economic-centered ideology, particularly the social sterile environment of institutional care, remains a challenge for the professionalization of eldercare services. As I mentioned in Chapter 3, professionalization should combine the systematic care approach and the person-centered approach in practice. Non-state actors' advocacy for relational care to maintain the personhood of dementia sufferers is important to change the status quo of institutional care in China.

Transformations of Relationships

Each transition is related to transformations of relationships. These transformations involve: how personhood is constructed; how meanings of life are explored and interpreted; and how "good" death is conceptualized. As dementia sufferers' health conditions get worse and worse, care trajectories and transformations of relationships between caregivers and dementia sufferers are also influencing and shaping each other in important ways. A focus on who a person with dementia is, and the ways in which caregivers and care recipients interact, therefore, helps us to see how intergenerational conflicts and support as well as market cooperation can reconfigure values and redistribute roles and resources (Long and Campbell 2020). Furthermore, these transformations have to do with the altered meaning of life and death in contemporary urban China (Shea 2020). We often use the word "dying" to describe when a person is in the last few days or hours of life. Sometimes a death is sudden and unexpected. Many family caregivers of dementia sufferers express that they experience g a long-term pre-death grief since their kin gradually lose their abilities over the course of illness. However, a “good” death has less to do with the interpretation of dementia than with the preparation for death. In Shanghai, a “good” death is contextualized within the context of “good” care. Again, transitions of care largely depend on how family caregivers interpret the personhood of dementia sufferers, their relations, and associated meanings of life and death.

Local Constructions of personhood

Compared to the dehumanization of mentally ill patients in China (Guo 2008; Guo and Kleinman 2011), Ikels (1998) found that elders with dementia in 1990s were protected by high rates of intergenerational co-residence, filial piety, and cultural understandings of dementia as a natural aspect of aging. Two decades later, medicalization of dementia vaporizes the cultural protection, resulting in a stigmatization of this illness (see Chapter 1). Correspondingly, the public construct a different personhood of dementia sufferers. For instance, there is a division of the personhood of dementia sufferers in Shanghai. The lay public categorize dementia into two types: *aggressive* dementia (*wu* or 武) and *amenable* dementia (*wen* or 文). While both acknowledge the loss of cognitive abilities, such as in the forms of memory decline and confusion, the division captures behavioral differences that are related to two constructions of personhood of dementia sufferers. People with aggressive dementia are believed to have violent tendencies: being agitated, destroying things, hurting people, verbally abusing people, and showing no gratitude to family caregivers. Therefore, according to local residents, this group of people have lost their personhood. In contrast, people with amenable dementia have preserved their personhood even though they have cognitive impairments. This is because they have no violent tendencies and no verbal abuse, and they are easy-going and sometimes grateful to their family caregivers. This division is closely related to the dementia care burden, which not only generates different family strategies, but also lays the foundation to examine how the personhood of dementia sufferers is actually constructed locally.

Unlike Western societies where personhood depends on individual autonomy and cognitive abilities, in collective societies such as China, personhood is closely related to relationships, social positions, and moral status. Although Chinese elders enjoy a high level of respect from both family members and society, they are equally subjected to the moral responsibility of maintaining their personhood. One famous ancient saying goes, "If a senior does not respect oneself or others, a younger person has the right not to show respect (*wei lao buzun, wei you bujing*)." A senior should behave appropriately in line with one's age and social position. By doing so, he/she not only achieves one's moral status, but also maintains a harmonious relationship with other people. If not, the individual loses his/her moral status, which further destroys one's personhood. This unique construction indicates that one's personhood is achieved through one's endeavor, rather than a given status in Chinese society. People living with aggressive dementia challenge these behavioral codes, therefore, their personhood is damaged. Even though these aggressive behaviors have been medicalized to underpin one's changes with dementia, the lay public, including family caregivers, still employ behavioral codes to evaluate one's personhood. The biological categorization, no matter a neurodegenerative disease or a mental disorder, supports and even reinforces the cultural and psychological reasoning that dementia threatens one's continuity of identity. The public generally call this group of people “madmen,” “madwomen,” or “crazy people.” Family caregivers, who value harmonious relationships, often accept this interpretation of aggressive dementia.

Because of aggressive behavior and the associated overwhelming burden, taking care of dementia sufferers is more a responsibility than an expression of love or filial piety. In Chapter 6, I termed this phenomenon as “resigned familism” to reveal the paradoxical logic - family caregivers are neither fully resigned nor fully compassionate to caregiving. The construction of the personhood of aggressive dementia sufferers further testifies to this care practice. According to local residents, these caregivers, especially adult-child caregivers, were good people in many aspects to their kin. However, living with an aggressive dementia sufferer was “so challenging that no one can enjoy the time at home” (#036). According to an adult-child caregivers (#W20), “there is no affection between us. They [dementia sufferers] are the parents who drive filial children away!” Many family caregivers lamented that they could not bear the care burden, and some even expressed their resentment toward their parents. Two family caregivers (#W06 and #041) even swore that they would not shed a tear after their parents died. Although Chinese family expect adult children to show respect to elders, this respect is built upon harmonious order. Aggressive behaviors, regardless of senility, threaten the order, which further undermines one’s personhood and family relationships.

Because of aggressive behaviors, some family caregivers tend to institutionalize dementia sufferers. Mr. Cai (#007) eventually decided to send his wife to a nursing home after he witnessed these challenges. According to Mr. Cai, his wife screamed all the time, complained about ghosts at home, and sometimes threw things out of the window. Mr.

Cai could not sleep well and eventually had a heart attack. After that, their daughters, who had work duties, suggested Mr. Cai hire a nursing aide. However, after several trials, the Cai family failed because no nursing aide wanted to take care of an aggressive dementia sufferer who often physically hit strangers. “We have no choice now, and my mother has driven everyone crazy in our family,” said Mrs. Cai, the daughter caregiver in our conversations.

The aggressive behavior of dementia sufferers further challenge the capacity of institutional care. Although many nursing homes acknowledged that they offered dementia care when I conducted my fieldwork, in operation, some nursing homes set a high standard to minimize their risks of enrolling elders with aggressive dementia. Mrs. Pu (#036) had planned to send her husband to a nursing home because of his aggressive behavior. However, the nursing home rejected her husband because “he can still walk,” which meant a high risk for him to get lost. The nursing home Mrs. Pu visited, together with several other nursing homes I visited, expressed that they would rather admit those who completely lost walking abilities than those who had a high likelihood of getting lost to minimize their administration risks. “If a senior person has lost cognitive abilities but can walk, they will charge more than 10,000 RMB [1,400 USD] per month. If he/she cannot walk, they increase nursing fees but administration fees will be less. I will definitely send him to a nursing home when he cannot walk,” said Mrs. Pu.

Due to the misunderstanding of aggressive behavior (see Chapter 6) and limited public education on how to manage the aggression, there is a lack of public empathy toward dementia sufferers. Accordingly, the public deprive the personhood of people living with aggressive dementia. The reconstruction of an individual with aggressive dementia as a nonperson or less of a person is an instance of the extreme stigma in Chinese culture. The division between aggressive dementia and amenable dementia is not only an effort to differentiate subgroups, but also a reverse mirror for better understanding what a person should be in Chinese culture.

In contrast to the deprived personhood of people with aggressive dementia, family caregivers attribute different degrees of personhood to those with amenable dementia, ranging from a full personhood to an adjusted one. Full personhood is a metaphysical concept that illustrates degrees of capacity (Higgs and Gilleard 2015), and it is often used to describe those with early stage of dementia. Along with the progression of disease, family caregivers assign an adjusted personhood to those seniors with childish behavior. Compared to the full personhood that is stable, continuous, and opting for a moral status, the personhood of a childlike senior is contingent and relational. Even though there is a differentiation of behavioral capacities, the amenable tendency of these patients not only enables them to maintain a certain degree of personhood, but also mobilizes resources to maintain family-based care rather than their being institutionalized.

Amenable dementia sufferers achieve full personhood, according to family caregivers, through maintaining appropriate social relationships. Patients in the early stage of dementia preserve their social capacities, such as showing gratitude to other people, which is a key component of personhood in Chinese culture. They might not catch fast conversations or perform well in tasks that require intensive mental labor; however, they can express “sorry” and “thanks” to show their basic social etiquette to people. Moreover, the ability to do something or to contribute to something also protects the personhood of dementia sufferers. For example, Mr. Ding (#026) took care of his wife who was diagnosed with early stage of dementia. Each morning this couple went to the food market for shopping. When Mr. Ding tried to buy some expensive meat or fruits, Mrs. Ding would persuade him not to do so. When Mr. Ding intended to buy expensive things to treat her, she would say "thank you for being so nice to me." In our conversations, Mrs. Ding, even though she had memory problems, constantly appreciated her husband's good deeds simply because "he cooks meat for me every day." Mr. Ding said, "She has been thrifty for her whole life. She never bought herself fancy clothes, and was never jealous of other people's lives. Because she is the person who can share weal and woe in life, I will take care of her." Rather than emphasizing autonomy or rationality, full personhood is attributed to an individual who can maintain basic social relationships, which further justifies one's moral status.

One important behavioral change during the course of dementia is that patients become more childish. Even so, family caregivers assign an adjusted personhood to those childlike seniors given their sustaining relationships. In Chinese language, "old child" and "childish behavior" are often used to describe seniors returning to their original status when they were children. Childish behaviors of dementia sufferers include: limited ability to make judgement, limited speech or word choice in conversations, being naïve to various conditions, etc. Although there might be an overlap with aggressive dementia, the peaceful mind, beautiful faces, and the simple affection of amenable dementia sufferers often remind family caregivers how innocent their kin are. In contrast to aggressive behavior, their amenable behavior establishes an adjusted personhood that not only justifies their needs, but also catalyzes the empathy from family caregivers. For example, Mrs. Wang (#059) took care of her mother for almost five years. She had poor memory and often repeated the same question. According to Mrs. Wang, her mother was different from those with aggressive dementia:

> She becomes a child and often calls me "mom" when she needs something. When I tell her that I will go to hospital for her medication, my mom will say "thank you." When I ask her to go out with me, she will say "no." You see, she can communicate with you, which makes me feel grateful.

The childlike behavior of Wang's mother and her ability to maintain basic conversations construct an adjusted personhood. The amenable tendency of this group of people enables the sustainability of their relationships with family caregivers, and thus the continuity of family-based care. For some spousal caregivers, this dependent relationship can revert to one in which caregivers are in need of the presence of their spouses with dementia. The reverse relationship of care *giving* and *receiving* not only expands our understanding of the personhood of dementia sufferers, but also challenges the conceptualization of "care," which I will discuss in the following section. Because of amenable behavior, dementia sufferers often become more dependent on family caregivers and constantly follow them like a "shadow." For instance, Mr. Huang (#015) had taken care of his wife for more than ten years. Many people suggested that he should send her to a nursing home considering the increasing care burden. Mr. Huang did not want to because "I will feel lonely if she is absent." Mr. Huang also treated her like a "spoiled child":

> I cannot understand what she says, and she cannot understand what I say. But, she feels great when I compliment her. She cannot recognize many family members, but she knows me and calls me "dad." She is quiet when

> I am around. If not, she will cry. It's really hard for me to send her to a nursing home.

Mrs. Huang's amenable behavior was a powerful testimony of her personhood. Although she had poor cognitive abilities, she expressed her needs of conjugal love through watching and shadowing her husband. Mrs. Huang's childish behaviors, such as crying, liking praises, and calling her husband "dad," might reduce her full personhood from outsiders' perspective. However, these behaviors catalyzed the empathy from her husband. Moreover, Mrs. Huang became quiet when this couple was together, which made Mr. Huang feel being needed. Thus, the presence of his wife formed their dependent relationship, i.e., being mutually needed.

Because of the mutually dependent relationship, many family caregivers feel that their endeavor is worthwhile when they receive positive feedback from dementia sufferers. Mr. Zheng (#099) took care of his wife who was diagnosed with dementia five years ago. According to their daughter, he often felt depressed due to his wife's dementia conditions. Mr. Zheng, however, expressed that he felt rewarded when his wife had a smile on her face. Even though she could not speak, the smile represented appreciation for his caregiving. "She cannot express, but I know what she wants to say. It's not about she needs me. Rather, I need her more than she needs me. If she is absent, I will feel even lonelier," said Mr. Zheng. People living with amenable dementia do not threaten their personhood too much since their relationships with family caregivers are well maintained. Sometimes, their relationships are strengthened because of the mutual need. Clearly, the mutual dependency protects amenable dementia sufferers from being institutionalized.

The division of attributing different types of personhood to dementia sufferers captures how personhood is locally constructed and how care is influenced by these constructions. People with aggressive dementia lose their personhood because their aggression threatens harmonious relationships with people. Therefore, family caregivers are reluctant to take care of them, and sometimes generate resentment toward their aggressive kin. Correspondingly, there is a high tendency for aggressive dementia sufferers to be institutionalized. Not only domestic settings but also nursing homes do not allow interruptive behavior. Some nursing homes set strict criteria to minimize the risk of enrolling aggressive dementia sufferers. By contrast, amenable dementia sufferers are attributed to a full or an adjusted personhood due to their harmonious relationship with family caregivers. Even though they have lost their cognitive abilities, their amenable behavior is more easy to deal with and more controllable. Their ability to preserve harmonious relationships with nearby people also attracts more love, care, and respect. As a result, family caregivers continue the family-based care arrangement and try not to institutionalize their kin.

The division of personhood of dementia sufferers is one aspect—the behavioral perspective—that underpins the transformations of relationships along with care trajectories. For most dementia sufferers, their conditions fall somewhere in between, or the dichotomy classification does not fully capture the complexity of their experience. In the next section, I will continue to explore the transformation of relationships between caregivers and care recipients during care trajectories.

Explorations of the Meaning of Life Changes

Because a large portion of the care trajectory takes place within domestic settings, it is important to examine how family caregivers make meaning of their life changes, such as the onset of dementia and the deterioration of illness, and how the interpretation of their relationships with dementia sufferers affects care trajectories. Caregiving is a process of reconstructing the relationship between dementia sufferers and their caregivers (Karner and Bobbitt-Zeher 2006). Dementia affects both patients and family members who are providing care or supporting primary caregivers. During this process, caregivers and other family members struggle to negotiate the disorder of illness and reconstruct meaningful relationships and lives. Eventually, their care practices are transformed from the previous biological treatment to daily life support, and from dealing with a "disaster" to creating meaningful ways of life. It is the meaning of life that determines family caregivers not only to frame out best solutions to improve care outcomes (see Chapter 5), but also to struggle to maintain existing family-based care arrangements.

As caregivers reflect on and narrate their experiences, they often start with the changes they have witnessed in patients through the course of illness. By representing the person that existed in the distant past, caregivers invoke memories of who the patient was before he/she became afflicted with dementia. As Mr. Wang (#069) explained, "She used to be very smart, and had done fine processing and accounting. She was diagnosed at an age of 67, too young to develop dementia. Now it has been three years, and she does not know how to eat, drink, and sometimes soils the bed. It hurts me when I see she is deteriorating." Caregivers offer accounts such as these differences between the familiar person and the dementia-engulfed person to signify the extent of their loss. Narratives often focus on unfamiliar, inappropriate, and embarrassing behaviors to illustrate the disorder that the illness has brought to their families.

Gradually, family caregivers begin to reflect and reorient themselves to the changes in their daily lives. They become more active by taking on more responsibilities for the ill individuals. This process can develop out of the conjugal relationship or mutual support between generations. Thus, it is a natural outgrowth of these relationships when family members perform activities that are defined as "caregiving." The time when they realize that they are doing caregiving is when they find themselves constantly called upon to do tasks that patients were previously good at. Some caregivers are explicit about the changes in their own identity that develop as they respond to the needs of their relatives. Mrs. Li (#044) was 55 years old and had taken care of her husband for about three years. When recalling changes of her life, Mrs. Li stated:

> He has changed a lot. Previously, he was good at cooking, then I found he constantly made mistakes, and eventually he lost his interest. His writing, too. We moved to a new apartment last year. Most men are able to do basic housing maintenance, but he could not. I have to deal with all of these rapid changes by myself. Sometimes, I lost my temper and yelled at him. He did not say anything. I now have to shoulder more responsibility. In order to take care of him, I requested an early retirement three years ago. Now, I am a fulltime caregiver.

Her assertion, "I am a fulltime caregiver," denotes the completion of the identity shift from the familiar role of being a spouse to her new status as a caregiver. She acknowledges her husband's illness and, in response, redefines their relationship as one of caregiver and care receiver. By reconfiguring a transformed, yet still relational, identity with her husband, Mrs. Li artfully negotiates the affliction of dementia on their daily lives. Being a fulltime caregiver means Mrs. Li embarks on a new mission. Although she no longer plays the traditional role of being a wife, Mrs. Li does not have to create a separated identity to live apart from her husband.

Familial relationships are a salient component of an individual's identity, and any change to these relationships will cause a transformation of one's identity. Some caregivers identify their transformation as a response to their kin's needs. Caregivers narrate their new relational configurations in an attempt to make sense of the contingency of illness and the interruption of their relationships. Mr. Cao (#043) and his wife had been married for more than fifty years. Previously, it was his wife's responsibility to do all household chores and manage the whole family. Eight years ago, his wife developed mild cognitive impairment, and her condition worsened recently. She completely lost her ability to care for herself. Mr. Cao expressed his ambivalence of being a dementia caregiver:

> I do not complain about taking care of her. But her illness causes our whole family to be unsettled. When she looks "normal," she is easygoing; however, when there is an outbreak, you will never know what will happen. When I was cooking dinner yesterday in the afternoon, she came over here. I could not hold my tears when she said "thanks." That was the first time she expressed gratitude to me. However, in the evening, she could not tell where she was and started to yell at me, asking why I brought her here. Just over several hours, her condition changed so fast.

The feeling of ambivalence often creates a tension between the remembered past and the reinvented present, and between a familial identity and the identity of a caregiver. With the deterioration of illness, dementia sufferers often lose their awareness of their previous relationship and have no collection of the people around them. Speaking of her husband, Mrs. Xu (#047) said, “He does not know me anymore. He might not think I am his wife. Sometimes he calls me by his colleagues’ names. So, I think it is time for me to hire some home aides to help.” Having lost the ability to recognize his previous relationship with his caregiver, the ill patient constructed each interaction as a new one, which compelled Mrs. Xu to think about alternative care. However, the wife caregiver was still cognizant of their past relationship. This led to a dilemma: should Mrs. Xu continue to take care of her husband or pursue personal life? After more than ten years of caregiving, Mrs. Xu tried to find a balance between these two:

> When he hit me, I would run away. Sometimes, I could not run immediately, he would hit me so hard. I don’t lose my temper because I know he is sick. I try not to see him for a while. I close the door of my bedroom to play piano or paint for a while. I regain the sense of myself there. I have to find things meaningful in life. Otherwise, it will be too hard to live with him.

Creating a private space at home while keeping one’s social responsibility is one way to escape the burden and add value to everyday life. A private space can help Mrs. Xu “regain the sense of myself,” in which she enjoys a moment of peace. Compared to the real world of caregiving and confronting the ill partner, the private space seems a paradise without suffering. After Mrs. Xu was alone for several hours, she would be refreshed mentally, physically, and emotionally. She felt restored and could then face challenges of the real world.

While acknowledging that the increasing care burden might intensify family relationships, in some cases, challenges of dementia care become an opportunity for family unity. In some families, it is the disease condition—a threat to the wellbeing of the whole family—that unifies all family members to transform the “disaster” to meaningful ways of life. Junior Cai (#081), aged 38, recently quit his job to help his mother take care of his father. Senior Cai was diagnosed with dementia four years ago. Originally, Mrs. Cai took care of her husband. It became challenging after Senior Cai developed aggressive behavior. According to Junior Cai, his father often became violent toward his mother without any reason. Senior Cai refused to take medicine, and sometimes he would physically hurt his wife. After witnessing these challenges, Junior Cai, the only child of this couple, decided to get involved. When Senior Cai became aggressive, unlike other caregivers, Junior Cai would become even more aggressive and threaten his father. Surprisingly, his father often calmed down in these conditions and followed his suggestions after going wild for a while. When I asked Junior Cai about the rationale of his strategy, he explained:

> My mother is too weak to handle these challenges. She does not know how to manage my father’s aggression. She only knows medicine and to give him drugs. There are so many nonpharmaceutical strategies. I am trying to persuade my mother to change her mindset to deal with my father’s aggression by nonpharmaceutical strategies, but it is extremely hard for her to change. That’s why I have to quit my job to get involved.

The Cai family united to deal with the patient's aggression. The mother knew medicine, and the son was good at nonpharmaceutical strategies, especially psychological methods, to manage his father's "bullying" behavior. Combining these two strategies addressed these challenges and maximized care outcome, i.e., for the benefit of patients. Whether these strategies are good depends on how families interpret them. Junior Cai was outcome-oriented and believed that "we need to change our communication strategies" to manage his father's behavior. Unlike his mother, Junior Cai took a strong attitude toward his father with a good intention. According to Junior Cai, "If you do not take medicine and food, how can you become better?" So, he had to get involved to improve care outcome. It was the improvement of Senior Cai that united both the mother and the son together. Eventually, the seemingly "bad" care was transformed into a form of "good" care.

This care *giving* and *receiving* relationship will sometimes continue to change after years of illness. As I mentioned in the previous section, caregivers and care receivers developed a mutually dependent relationship to continue family-based care. Mr. Huang (#015), the husband caregiver I mentioned before, expressed that, "Because she [his wife] is here, I have something to do every day. If she is absent, I will feel life is meaningless. It's better to have a wife. A home without a wife is not a home anymore." Similarly, Mrs. Hong (#017) could not deal with home change after she sent her husband to a nursing home, "It has been 48 years for us to live together. Originally, it was extremely hard for me to live apart from him. I have gradually adjusted to that now. I talk to his picture when I miss him. When I sleep, I hold his pillow. It is the reality, and I have to cope and accept it." For seniors, home is not a building or an asset; rather, home is a concept with personal meaning and a sense of belonging. It is the people who are living there that make the place as a home. The mutual attachment and shared memory and experience make home a special place that social spaces (e.g., nursing homes, hospitals, senior centers, etc.) cannot be compared to. Understanding this is important since most seniors do not want to leave home for institutional care. No matter how good infrastructure nursing homes have, they cannot replace the familiarity of home from seniors' perspective. Leaving one's home for another place is a disruption of the familiarity for dementia sufferers. Therefore, the significance of home should be highlighted in assessing the care seniors need and how to deliver it.

Because of the mutual dependence between spouses late in life, some family caregivers have to change their home environment to continue family-based care. Mr. Zhou (#083) had been taking care of his wife for about one year and half. Confronting the illness, he found himself compelled to interact with her in a new way. Mrs. Zhou was especially suspicious about her husband's intention when he talked to other women. She was constantly worried about whether her husband was having an affair and often became sexually aggressive. Mr. Zhou could not satisfy all her needs, but he wanted to continue to take care of her. Realizing sleeping separately was impossible, he asked their daughters to replace the original large bed with two small beds. "Our bedroom is like a hotel room," said Mr. Zhou. When I asked him why he did not send his wife to a nursing home, Mr. Zhou explained, "I could not sleep without her." Sleeping is especially challenging for spousal caregivers when their ill partners have interruptive behaviors. Mentioning that sleeping in one room with two beds, Mr. Zhou realized that, as a husband and a caregiver, he could no longer act as before because his wife was different now. Rather, he should become a more responsible and directive person in this relationship. Though no longer playing the traditional marital role, Mr. Zhou did not move out or send his wife to a nursing home because of their mutual dependence. The strategic adjustment of their bedroom made their marital relationship continue in a healthy way for both.

Family caregivers struggle to make meaning of life changes along with the onset and progression of dementia in order to maintain family-based care. They have to adjust themselves to the familiar yet new identity as *dementia* caregivers. When the increasing care burden threatens their relationships with their kin, some caregivers begin to think about alternative care. However, no matter how challenging dementia care is, most family caregivers are able to identify the meaning of their relationships with their kin, which is the key to continuing family-based care. Because of the transformed meaning of the caregiving and care receiving relationship, family caregivers have to reconfigure the home environment to continue the family-based care. Strategies that are constantly mentioned by family caregivers include taking care of plants, raising pets, changing colors of furniture, living and playing with kids, removing locks in bathrooms or bedrooms, etc. These strategies not only serve as key components of dementia care, but also demonstrate how dementia care unfolds.

Contextualization of "Good" Death

Death should be the closure of care trajectories. However, interpretations of "good" death and the ways to achieve it further complicate the practice of dementia care. This section is about how family caregivers conceive "good" death for dementia sufferers. Death and dying were originally not my primary concerns during the fieldwork. In Chinese culture, it is a taboo to discuss death in public settings, especially when directly talking to seniors. Death became a concern when I encountered several family caregivers who experienced the loss of their kin. Among the 106 family caregivers I interviewed in the memory clinic, two experienced the death of their kin in 2017; and among the 38 families in the community where I did my research, five families lost relatives from 2015 to 2017. So, I had an opportunity to talk to these caregivers about their experiences of losing their kin and their opinions about “good” death.

According to local residents, a “good” death should be without too much pain and should not be a burden on their families. As in the opening vignette, compared to the dementia sufferer, the spousal caregiver had a “good” death since she experienced limited pain and did not burden any of her children. I was originally shocked to hear this definition of “good” death. But this definition was given within the context of dementia sufferers who themselves had not only experienced much loss and pain, but also brought a heavy burden on their families. By this definition, some residents rank death in an order of their preference: heart disease first, cancer second, chronic disease without cognitive impairment third, and lastly, the worst death, dementia. Compared to death itself, residents care about the period of being engulfed by pain first, and then the associated care burden. Since an individual with heart disease often dies suddenly and more quickly than cancer patients, people believe that an individual with heart disease might experience the least degree of pain among all chronic illnesses. In addition to the pain, cognitive intact is another factor affecting a “good” death, which is closely related to the burden on others and the dignity of individuals. Although individuals with chronic illnesses will inevitably place the care burden on families due to the decline of physical abilities, the burden of dementia care is much more overloaded than other chronic illnesses due to the nature of the disease (Kim and Schulz 2008). Moreover, compared to dementia sufferers, people living with other chronic illness without cognitive impairment have a chance to express their will and die with dignity. According to local residents, dementia sufferers, especially the aggressive type, lose the dignity of being human, and thus, their death is the worst.

Is this logic applicable to families who experienced the loss of their relatives with dementia? Not exactly. The above definition of a "good" death serves as merely a fantasy. The real world is more complex than this. Since dementia cannot be cured and patients often cannot express their wills about death, "good" death is defined by family caregivers. Adult children and spouses often define a "good" death differently. Adult-child caregivers often construct "good" death from a practical and rational perspective, e.g., "no regrets," "some basic enjoyment of pleasure," "a completion," and "the wholeness of the body," Whereas spousal caregivers often view "good" death from relational, moral, and emotional perspectives.

For spousal caregivers, a "good" death is an emotional closure for both dementia sufferers and their caregivers. For most spouses, it is almost impossible to achieve this closure. Mrs. Hua (#W21) could not stop missing her husband after his death. Six months later, I visited her and suggested Mrs. Hua stay with her three adult children for this emotional transition. She insisted on living in her old apartment and waited for her husband's spirit to "come" back and offer a closure, "He left me alone. I stay here like a fool. I cannot stop missing him at night. I called his name, hoping he could come back and visit me again, even his spirit!" From outsiders' perspective, we see Mrs. Hua's bereavement of losing her husband. However, inside of her bereavement is her interpretation of a "good" death. According to Mrs. Hua, a "good" death should be a continuation of the previous relationship. Even though death itself separates the couple, the spirit of the dead can transcend the physical world to sustain the relationship. This folk belief used to be very popular in ancient Chinese culture, especially Buddhism. But, it seems a little bit outdated in contemporary China where materialism seems applicable to everything. As a Buddhist, Mrs. Hua drew upon this traditional belief to make sense of her husband's death and her bereavement. She complained about her husband's spirit, which failed to "come" back home. As a result, Mrs. Hua could not achieve an emotional closure with her husband, which caused her enormous suffering. Therefore, it is meaningless to objectify death from the perspective of the dying in terms of pain and dignity.

A "good" death should also be a mutual agreement on how to die. However, unlike other cognitively intact persons, individuals with dementia in later stages often have lost their ability to express their will about what kinds of death they want, leaving this difficulty up to their relatives.[45] Compared to adult-child caregivers, spousal caregivers express and experience more challenges to respond to the death of their loved ones. Mrs. Sun (#W04), at an age of eighty, had to say "goodbye" to her husband after more than ten years of caregiving. When I saw her again after one year she lost her husband, she was still uncertain whether she had done enough for her husband. When her husband was hospitalized for a pneumonia and had difficulty breathing, she refused to perform rescue intubation techniques because of their economic circumstances. In other words, she

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[45] The death culture in China also prevents adult children to talk about it directly with their parents.

literally witnessed her husband stop breathing in the last second. After her husband died, Mrs. Sun constantly talked to other people about her moral failure of not being able to rescue her husband. “If he could tell me that he did not want a tracheotomy, I would follow his will. He could not be able to say a word!” said Mrs. Sun. Without a pre-death agreement, it was impossible to achieve a “good” death, regardless what she chose. If she decided to rescue her husband, then the enormous financial burden would be on her children who were financially struggling. If she gave up the rescue, she had to bear the psychological burden all the time.

Compared to the difficulties of achieving a good death for spousal caregivers, adult-child caregivers tend to be more practical and rational. In similar situations, gauging whether to perform invasive rescue techniques, adult-child caregivers did not express their moral failure when their parents were dying. Mrs. Bai (#W06) said, “Physicians asked us whether we wanted to rescue our mother. We said no. We wanted our mother to peacefully leave after about sixteen years of suffering from dementia. She did not know she had dementia when she was alive. If she knew that, she might kill herself. By the way, she was 96 years old. We wanted to keep her body in whole when she died. We did not want to have many tubes in her body.” Similarly, Mr. Sun (#W24) believed it was meaningless to rescue his mother when it was time for her to die:

> Everyone will die. I gave her good food, drinks, and medicine during caregiving. When I learned that there was no cure for dementia, I gave up the treatment. Since I did not have money, I did not send her to the hospital for rescue. Even if I had money, I would not allow intrusive

> procedures. It's a waste of resources, and she also had to suffer. It's meaningless when it was time for her to die.

Practical and rational caregivers believe that a "good" death is less related to modern medical technologies than everyday good caregiving, particularly when financial resources are limited. Mrs. Xi (#041), who, along with her husband, had been caring for her parents-in-law for more than six years, explained more about a "good" death:

> They [her parents-in-law] have been suffering throughout their whole life. When they were young, there was limited food; when they got married and had children, they had to save for their children; and when they were old, they developed various chronic illnesses. There was no time for my parents-in-law to enjoy life. I prepared various vegetables and fruits every day to make sure they had eaten well. My father-in-law died last month. It was a good death since he had eaten some good food.

Adult-child caregivers believe that people should enjoy an adequate life after life-long suffering. Even though seniors have many chronic illnesses that might prevent them from having "good" food, they are eligible to eat whatever they can after managing health conditions well. If they can make a balance of pleasure and suffering, then the death should be "good," and their lives are "complete."

Sometimes, a death might not be a completion when there is something left undone, especially for an unexpected death. For example, Mr. Zha (#054) had taken care of his mother for more than ten years. In order to take good care of his mother, he prepared a lot of medicine to manage her dementia condition. Unexpectedly, his mother died from heart failure, leaving many drugs at home. According to the local standard, Mr. Zha's mother should have a "good" death. One month after his mother's death, Mr. Zha showed up in the memory clinic and told me that, "When she was alive, I took care of her day and night without a moment of thinking about myself. Now, after she died, I feel even more tired than before. It seems that I haven't done enough for her." The sudden death results in an incomplete relationship with the son caregiver. Unlike other adult-child caregivers who often expressed relief after their parents' death, Mr. Zha could not feel that, since he "hasn't done enough for her [his mother]." The case of Mr. Zha shows that, the two versions of "good" death—spousal caregivers' emotional, relational, and moral orientations and adult-child caregivers' emphasis on pragmatism—are not mutually exclusive. Rather, they are exchangeable within a particular context.

A "good" death for dementia sufferers is more about a preparation than an interpretation. Yet, not every family can prepare well for the death of their kin since one's decision is subjected to both family politics and their social environment. A daughter caregiver, Mrs. Lv (#062), who was taking care of her mother, told me that her father-in-law was also diagnosed with dementia. In contrast to her primary role in preparing for her mother's death, she and her husband had almost no say on her father-in-law's death. Her father-in-law was in a vegetative state in a hospital. According to Mrs. Lv, "he is ready to die at the advanced age of 93." However, his three biological children could not make this decision since he was remarried. It was their step-mother's decision to sustain his life. What made things more complex was that the father-in-law was an upper-level cadre who participated in the Civil War. Mrs. Lv explained, "many families like us who have upper-level cadres will not let them die, not only because they have free medical care, but also because they want to get more pension from the state." Without a decision-making power, the three adult children were opted out of their father's destiny. Life-sustaining techniques in this condition have nothing to do with the financial burden or moral dilemmas; rather, they become a way of making a profit.

A "good" death should include a witnessed death of the body, particularly for dementia sufferers. As we all know, dementia patients often get lost as they lose their orientation abilities. Even though there are various techniques to track where they are, no one can ensure that their kin will not be lost. When I did my fieldwork, the news often reported seniors who were lost or families having lost their kin. Often, they could find them after a couple of days. But, in extreme situations, families would not found them for a long time. When I began writing this chapter, CCTV-13 released a report that a husband in his seventies was trying to find his wife with dementia who had been lost for eighteen months (CCTV 2019). During my fieldwork, one of my informants got lost but was found almost three days later. Families, relatives, neighbors, policemen, social workers, volunteers, and public media producers were all getting involved to find the patient. We all experienced anxiety and worry during this period. I could not imagine how much pain this old man, in his seventies, had experienced during the eighteen months. According to his statement in the news, he would continue to try every method till he found her. What about the situation if he could not find her? In the memory clinic I interviewed a patient who had mild cognitive impairment. During our interview, I learned that his mother was also a dementia sufferer but was lost ten years ago. He and his families tried every method to find her but failed. According to this patient's statement, if the person was not found within two years, then, her hukou would be withdrawn based on some civil affairs' policies. The police system would then officially announce the “social death” of the person. A “social death” implies the most pervasively threatening thing that can happen to dementia sufferers. Unlike the Western conceptualization of “social death,” in which the body remains attached to an individual with dead mind (Waskul and van der Riet 2002), here it refers to “the unwitnessed death of the body, and unwitnessed living of the person” (*si bu jian shi, huo bu jian ren*). It is the worst death according to this family caregiver.

Compared to the logic of “good” death constructed by local residents, various definitions of “good” death for dementia sufferers have less to do with pain and dignity than with “emotional closure,” “moral completion,” “good food,” “enjoyment of life,” “preparation,” and “witness.” For the current senior generations, particularly for those who have experienced war, hunger, political turbulence, and dramatic social change, suffering has always accompanied their lives. For these seniors, dignity is less important than survival. “Good” death is about a completion—both spiritually and bodily—of the life for dementia sufferers, and a completion of the obligation of family caregivers. Therefore, “good” death is inevitably related to deliver “good” care.

Conclusion

This chapter has examined transitions from solo caregiving to institutional care. Along with the trajectories are transformations of relationships, in which local constructions of the personhood of dementia sufferers, explorations of the meaning of life changes, as well as the contextualization of “good” death are presented. The examination of care trajectories and transformations of relationships provides an opportunity to reevaluate the disorder of the illness and recreate the meaning of life. Narratives that try to make sense of care reconfigurations and the morality tales of transformation from disorder to order prompt feelings of empathy toward dementia sufferers and their caregivers. Local constructions of the personhood of dementia sufferers reflect a contingent disorder—rather than an inherent disorder—that could threaten the bounded system of body, family, and society. Within the bounded system are explorations of the meaning of living with dementia, from lamenting the loss of their kin, the ambiguity feelings of caregiving, the mutual dependence between caregivers and care receivers, and eventually to embrace dementia as part of life. These explorations determine whether family caregivers should continue family-based care or seek alternatives. Standing outside of the bounded system is the conceptualization of "good" death. Even though dementia is ranked the worst death condition by local residents, various forms of "good" death for dementia sufferers are a negotiation of the disease, and a reevaluation of the meaning of life. Together, local constructions of personhood and various forms of "good death" for dementia sufferers exist as both an ideology and a structure of care.

Chapter 8 Moral Encounters of “the Generation in the Middle”: Dilemmas and Strategies in an Aging Society

Mrs. Mo (#W37), one of my hosts in Shanghai, was 59 years old and served as the director of a neighborhood in the community I researched. She took care of her 86-year-old mother and her two-year-old grandson. Her husband was 60 years’ old, but had to continue to work to pay off the loan on their new apartment. Mrs. Mo frequently thought about her own future care and complained that:

> The government said they would take charge of our eldercare when they implemented the One-Child policy. Now, when we are getting old, the government changes its statement and says families have the eldercare responsibility. How can we ask our only daughter and her husband to take four elderly parents and their only child while working?! It’s impossible! We have to go to nursing homes when we are too old. There’s no other solution!

Mrs. Mo’s situation is typical among many Chinese families where the middle generation has to shoulder multiple burdens of care as I mentioned in earlier chapters. Given the sociocultural context, I argue that family caregiving is not only a burden discourse in which dementia care is constructed and practiced, but also a moral encounter that involves one’s rational of care *giving* and *receiving*. In this chapter, I examine family caregivers’ moral dilemmas and how they solve these dilemmas during caregiving.

One aim of this chapter is to highlight moral controversies between continued emphasis on traditional norms and modern values. The family's role in society—which historically was an important mediator between the individual and the state on eldercare—once again, will be expanded to deal with the increasing elderly population. That is, the Chinese central government mandated that family should take the responsibility of eldercare in 1996 and renewed this legislation in 2013. The question is, to what extent can the family's position and function be expanded to meet the increasing care needs in a rapidly aging society? Alternatively, will the younger generation of Chinese who were born under the One-Child policy and held different values be able or willing to carry the moral responsibility for eldercare? The answer is uncertain now, but the future is bleak for most family caregivers, as Mrs. Mo indicated. Since these caregivers are subjected to both traditional values and principles of modernity, moral controversies that arise from caregiving will affect how they view and practice care.

The second aim of this chapter is to examine how family caregivers deal with moral dilemmas, particularly how they navigate their beliefs under divergent circumstances to maintain a coherent worldview. I call these caregivers "the generation in the middle" to highlight their unique life experience and moral encounters. "The generation in the middle" originally referred to those who find themselves in the role of caregiving for older parents while also fulfilling obligations to children and perhaps work. The public media often portrays this generation as "the middle layer of a sandwich." Circumstances can vary from individual to individual. In Shanghai, as the life expectancy increases, the middle generation has been shifted to refer specifically those who have retired or are going to retire, but having both older parents and grandchildren in need of care. In other words, “the generation in the middle” involves four generations, instead of three. This image generally refers to those families who have to confront competing obligations. Among the 144 families, fifteen families were actually in such a challenging situation, and the rest families had either gone through or were waiting to take on the challenge.

I borrow this image and elaborate it in the Chinese context where both traditional, modern, and post-modern thoughts coexist. Given the complexity of the situation, “the generation in the middle” here mainly refers to those who were born in and before 1960s and have survived into the 21st century. The “middle” situation not only refers to their multiple care burdens but also their moral realities. We can roughly periodize the life of these caregivers at least into four stages. At a young age, they were trained in traditional Confucian values; later they experienced radical Maoist ideology during the Cultural Revolution; and next they faced with individualism during modernization. In the post-reform era, there is a notable revival of all forms of religiosity and faith (Gao and Qian 2019; Szonyi 2009; Zhao 2010), which I tentatively consider as the fourth—post-modern—stage affecting the moral life of this generation.

China, while classifies itself as an atheist state, has experienced a revival of traditional beliefs. According to the Contemporary Chinese Religious Report (Lu 2014), more than 6.75% of the total population identified as Buddhists, almost twice the size of any other religious identities. Christianity ranks as the second most popular religion, which makes up about 1.9% of China’s population. My study also reveals a similar trend statistically. Among the 144 families, ten family caregivers (6.94%) identified themselves as Buddhists, and five family caregivers identified themselves (3.47%) as Christian. Although the rest of the family caregivers did not express specific religious beliefs, some referred to Confucianism as a guideline for their daily care. Together with other forms of morality, the revival of traditional beliefs creates techniques for cultivating moral characters. In this chapter, I pay attention to how family caregivers deal with controversies and cultivate moral characters.

I argue that rapid social transformation in China has not only created moral controversies, but also catalyzed a new form—and revitalized old forms—of morality to deal with them. Family, as the central domain of moral life, has been constantly reconfiguring its structures to meet both social challenges and individual desires. Family caregivers employ various techniques of morality (e.g., traditional beliefs and self-care) to dissolve controversies and cultivate moral characters. Stories of family caregivers illustrate that controversies related to family life are not only related to the morally divided society, but also associated with their ethos and subjectivities. I argue that, despite contradictions and discontinuities, the emergent forms of morality do not necessarily transform Chinese society from a morally divided one to an integrated one. Rather, these forms of morality should be understood local responses to the perplexing social changes or a coping mechanism to the oppressive conditions. Correspondingly, moral characters are often formed, cultivated, and negotiated at the intersections of state power, capitalist economy, family solidarity, and individual subjectivity.

Anthropological Approaches to Morality and Relations to China Studies

Two main anthropological approaches exist to study moralities: one is the Durkheim approach, which emphasizes moral constraints (e.g., duties, obligations, sanctions, etc.) that society places upon individuals (Hamdy 2012; Howell 1997; Laidlaw 1995; Robbins 2004; Yan 2009, 2012); the other is the Foucauldian approach, which highlights the individual ability to produce ethical subjectivities (Asad 1993; Lambek 2010; Mahmood 2005; Throop 2010; Widlok 2004; Zigon 2011). While one approach is interested in the moral structural sphere, formulating questions of power and resistance (Abu-Lughod 1986) and implying a moral relativism, the other investigates the agents' subjectivities, manifesting itself in various forms of ethical skills, such as religion (Asad 1993; Mahmood 2005; Zigon 2011), sentiments (Throop 2010), reasoning (Sykes 2009), and everyday ethical practices (Lambek 2010). Introducing the question of moral encounters, particularly moral controversies, interrupts the division of these two approaches. It draws attention to the integration of power, morality, and subjectivity shaping local articulations of morality. On the one hand, it offers an opportunity to examine dilemmas when individuals encounter with moral contradictions and discontinuities and what kinds of ethical skills they could adopt to solve these dilemmas. On the other hand, examining moral controversies enable us to understand the discourse of power that shapes various forms of morality, which further provides implications for the governance of life.

In the era of neoliberalism, the morality of eldercare has been fundamentally challenged. This is because care, which has been traditionally directed toward others, is now being directed toward the self. Traditionally, eldercare involves kinship practices that are shaped by local norms. However, rapid modernization and population aging have dramatically reduced the availability of family caregivers, resulting in the "crisis of caregiving" (Jesmin et al. 2011). The sustainability of family-based eldercare practice was also challenged (Brijnath 2014; Cohen 1998; Degiuli 2010; Ikels 2004; Lamb 2009). As a neoliberal strategy, self-care—namely, the individual responsibility for wellbeing and care of the self (Foucault 1987)—supplements the growing unavailability of family-based care. In developed countries, self-care has been integrated into the moral code. In developing countries, however, self-care is controversial since it challenges traditional norms such as filial piety (Ikels 2004), especially in the life of the household. So far, anthropological studies have not examined moral encounters or contending values related to self-care. Kleinman (2009, 2013) argues that caregiving should be interpreted as a moral practice, particularly a response to individuals who are suffering and unable to perform self-care. Therefore, an examination of the local moral discourse around self-care is needed.

An examination of the moral discourse of family caregiving in China is profoundly important. First, rapid modernization has created a "moral crisis" where collectivism and individualism interface with each other in shaping people's daily lives (Kleinman et al. 2011; Kuah-Pearce et al. 2014; Yan 2009, 2010). Numerous studies found that traditional Confucian values have been challenged by modern values emphasizing individualism (Hansen and Svarverud 2010; Liu 2017; Yan 2003b, 2010). Some studies revealed modified family practices in eldercare arrangements, such as embracing daughter caregiving, self-care, spousal care, and institutional care. (Chen 2016; Farquarh and Zhang 2005; Jeanne and Zhang 2016; Shi 2017c; Zhang 2006, 2009, 2017a), indicating a transformed moral discourse within domestic settings. Yet, few studies pay attention to moral conflicts of individuals who are currently caregiving for other family members and will be care receivers in the near future. Second, along with the economic reform, there is a notable revival of all forms of traditional beliefs, including Confucianism, Buddhism, Daoism, and Christianity "fever," indicating revitalized old forms of morality (Cao 2010; DeBernardi 2006; Lu 2014). Yet, few ethnographic studies have examined how family caregivers employ various forms of morality to solve dilemmas and make moral agents. Given the unique experiences of "the generation in the middle," an examination of their moral encounters during family caregiving is significant because: (1) it illustrates how the person is actually located in the economic, cultural, kinship, neighborhood, and work activities that define his/her moral orientations; and (2) it consists of contestations and compromises that actualize local values for benefits to both individuals and collectives (Dakin 2014; Kleinman 1999).

Moral Controversies of "the Generation in the Middle"

Two cultural schemes exist in China to regulate the function of family: filial piety, which is to serve one's parents (when they are alive or dead) with great respect and proper manner according to the rites, and collectivism, which is a communist ideology and requires individuals to subordinate to the benefits of family, society, and nation. Traditionally, these two schemes serve as an effective moral standard to manage tensions between family members or between family and society. However, with the expansion of social institutions such as social security, healthcare insurance, the pension system, and social eldercare, functions of families have been limited and adapted. In a rapidly changing society, the decline of family functions does not always couple with the development of social institutions. As a result, normative demands, family ideologies, objectives, and practices become contradictory.

Duties without rights

Although China has undergone tremendous transformation, filial piety, as a family norm, has been kept and modified to fit the needs of modern society. For example, the state mandates that families shoulder the eldercare responsibility in terms of daily support, financial care, emotional care, and health care. Legalizing eldercare responsibility has changed filial piety from a traditional Chinese virtue into a law principle. Despite this, family caregivers taking care of their relatives don't think that they are fulfilling the legal requirements; rather, they consider themselves to be endorsing a traditional virtue. Interpreting eldercare responsibility as a legal principle often occurs when one fails to do so. For example, in Shen's (#046) family, there have been conflicts regarding taking care of the elderly mother and inheriting her property for several years. The mother gave her housing property, pension, and savings to the son when she had a clear mind. However, as the mother developed severe dementia and often soiled the bed, the son failed to take good care of her. The mother had developed several decubiti due to the poor care from the son. The daughter, Mrs. Shen, could not tolerate her brother's abusive behavior and started to get involved in caregiving. Even so, there were still conflicts between the brother and sister. Neighbors all knew that the son had a poor attitude toward the mother and suggested that Mrs. Shen report her brother to the government. She had her own moral dilemmas:

> "I have thought about reporting him to the government and suing him to get my mother's property back. The question is that he remains my [biological] brother and it's better not to let everyone know in the neighborhood. Besides, it is my mother's will to give him everything. He should take good care of our mother. But, now, how can I watch my mother receiving poor care!? Anyway, Heaven is watching what we are doing. Someday in the future he will have to pay for what he fails to do."

Notably, family conflicts result from the imbalance between duties and rights among siblings. In order to address these conflicts, people in Shanghai have developed a new norm of "eldercare based on inheriting parents' property," as I discussed in Chapter 4. Although there are debates about this new norm, most families generally accept it when dealing with moral dilemmas regarding eldercare duties and individual rights. Often, adult children who receive their parents' property will fulfill their obligations; however, family conflicts arise when one intends to get benefits but fails to fulfill his/her duties. Shen was consciously aware about her brother's misbehavior, but she did not want to turn to lawsuits because of their biological relationship, her mother's will of property division, and the consideration of family face. Without any benefits, Shen continued to take care of her mother, even though she felt her rights were violated. In order to address the controversies, Shen turned to Heaven to justify her caregiving.

In addition to the above dispute regarding eldercare obligation and property inheritance rights, the boundary between work and care duties is equally unclear for adult children. While acknowledging that adult children have the legal obligation to take care of their parents, they are also subjected to work duties to maintain a basic living. Most family caregivers of "the generation in the middle" recognized the impossibility for their children to fulfill care obligation because "the competitive social environment does [did] not allow them to do so," said Mrs. Wang, the director of the senior center of the Bund. In response to the unclear boundary between work and care duties, Mr. Wu (MYCWu0328), who was both an NGO director and a nursing home manager, had appealed to the municipal government for more than ten years to introduce the practice of financially supporting adult children who were family caregivers for their parents. This plan was to encourage more adult children to take care of their parents and meanwhile to receive a minimum subsidies from the government. However, according to Mr. Wu, “It is [was] controversial because the government believes that families taking care of elders should be a cultural practice.” Again, it goes back to the unclear boundary between virtue and law regarding eldercare.

The unclear boundary between virtue and law in family-based eldercare leads to unresolved moral controversies among the public. An extreme case in the community where I did my research was that of a senior couple who wanted to rotate between their three sons for eldercare, with their housing and savings belonging to all three after their death. However, none of the sons wanted to provide care. Eventually, each contributed about 200,000 RMB [$28,000 USD] and jointly sent their parents into a nursing home. This case originally did not attract my attention since the couple were not dementia sufferers. Later, however, gossip and rumors circulated in the neighborhood. I learned that each son had his own business, and none wanted to sacrifice their career. In this case, adult children failed to fulfill their legal duties and were supposed to get punished. When I discussed this case with a local cadre, however, he showed his empathy to both the three sons and their parents. Like the three sons, the cadre intended to send his mother with dementia to a nursing home:

> It is extremely hard for two generations living together. My mother often stays active during night and sleeps during daytime. How can we live with her! I originally planned to take good care of her. But, it turns out she is my Everest! Now our government has overemphasized children’s care duties, but we also have to work! If we give up work to take care of elders,

> who will contribute to the economy? As long as elders are not mistreated, we should let it go! (HWJZhao0624)

While acknowledging seniors had the right to receive care from families, the local cadre emphasized younger generations' right to work. Correspondingly, while younger generations have to fulfill the duties of eldercare, seniors might need to relinquish the expectation of unconditional filial piety because their children have to maintain a living in a competitive society. The lack of enforcement of this legal responsibility results in controversies of how to organize eldercare within domestic settings, which in turn reinforces the unclear boundary between family-based eldercare as a virtue and a legal practice.

Scholars often describe adult-child based eldercare in China as a "repay" model, and self-care in most Western societies as a "relay" model (Ikels 2004). However, "the generation in the middle" is often caught in-between the two styles. Their parents expect to be paid back late in life for raising their children. "The generation in the middle," however, cannot expect to be repaid in turn—or having such an expectation seems outdated—because their only child often has multiple burdens to shoulder, and eldercare is clearly not their priority. As the opening vignette suggests, this generation believes that they are destined for nursing homes. Unlike their Western counterparts, they are unwilling to enroll into nursing homes. The unwillingness not only reflects their moral dilemmas, but also demonstrates the feeling of being abandoned by their families.

Collectivism without individual benefits

The Maoist ideology—collectivism—serves as another moral constraint for "the generation in the middle." During the Mao era, due to limited resources and political initiatives, an individual had to sacrifice for the family and the nation. Collective benefits superseded everything and any kind of individualism was attacked. People who have survived the Mao era were equipped with this mindset in their late life stage. Even though Chinese society has changed a lot, many family caregivers still endorse collectivism as a moral principle, and consider that individualism—particularly the pursuit of personal benefits at the cost of others—is a negative moral product of capitalism. For example, Mrs. Xi (#041), a Communist Party member, believed that "serving others serves oneself" (*renren wei wo, wo wei renren*). She was born before the Cultural Revolution, and experienced social chaos during that period. While acknowledging that Cultural Revolution was a wrong political initiative, she considered that collectivism should be distinct from the political context. She believed that "any selfish behavior or self-centered strategy will not solve family problems in China." Endorsing collectivism, she felt a strong moral responsibility for taking care of her parents and in-laws. This collectivism oriented ideology, however, does not align well with the modern individualism that is popular among the younger generation. When I asked Mrs. Xi about her future eldercare, she lamented that she could not receive care from her only son because he embraced individualism:

> When I make decisions, I will consider the feelings of others and try to make it fair. But, my son often behaves oppositely. Once it touches upon benefits, he will fight to favor himself. He has a high salary, but saves nothing. He always turns to us for financial support. When I got married,

> my husband and I bought our apartment; but now my son is going to get married, we have to buy him an apartment. How can we expect him to take care of us? It's impossible, and the younger generation is morally immature!

The discrepancies between parents' and children's value systems often result in a negative attitude toward the younger generation's ability to take care of others. Often, the younger ones are blamed for "having moral irresponsibility," "being too selfish," and "being too individualistic." While acknowledging that the younger generation indeed embraces individualism, some scholars argue that the forms of individualism are being distorted in the process of China's modernization (Liu 2017; Yan 2003b, 2010). Rather than emphasizing moral responsibility such as independence, the younger generation is often egoistic, who doing whatever they can for self-interests and without any socially-imposed morality. The distorted individualism creates ambivalences regarding whether one should expect eldercare from their children. Mrs. Chen (#049) was 81 years old and taking care of her husband who was recently diagnosed with dementia. During our interviews, I learned that she had "eaten various bitterness and given up all the sweetness throughout my[her] whole life." When she was a child, she was denied the opportunity to receive an education because she was the only girl in her family. When she grew up, she had to go to remote areas to support the local economy in Jiangxi during the Cultural Revolution. Although she could go back and forth between Shanghai and Jiangxi, she had to live apart from her husband and her two children for about twenty years. When she retired at the age of 45 and returned to Shanghai, she continued to work part time to support her children's education and career. When discussing her husband's diagnosis, she could not hold back her tears:

> My husband is sick, my son is divorcing, and my daughter lives very far from us and could not help. I am in my 80s and have never had a birthday party. Many colleagues asked me to buy a cemetery plot, I do not have such a wish. I told my children that I do not need any grave after I die, just a cremation, and throw the ashes in the Suzhou River. I have always been living for others, and I do not want to burden my children.

Subordination of personal benefits to the collective is the most salient feature of Mrs. Chen's life. Some people might think that those who endorse collectivism are relics from the Mao era who are motivated by collective goals and unable to participate in modern societies. These are misunderstandings about the senior generation. Many seniors, like Mrs. Chen, are actually equipped with modern thoughts in dealing with intergenerational issues. These seniors value the egalitarian relationship with their adult children and respect their decision-making, for example in getting a divorce. Moreover, these seniors embody themselves in consumer culture, such as buying a cemetery plot and having a birthday party. Yet, endorsing these modern thoughts does not make them less collectivistic or more individualistic. On the contrary, these seniors are consciously aware of the limits of their adult children's ability to provide such care. Emphasizing their unfulfilled wishes echoes not only the value discrepancies between the two generations, but also the ambiguities when one lives in a morally divided society.

Self-Care as a New Form of Morality

The phenomenon of self-care arises in a different context in China from that of Western societies. Self-care has become a central paradigm in Western societies. Scholars have described self-care as a neoliberal strategy proposed by the state to deal with population aging (Katz 1996; Neilson 2003; Powell and Biggs 2000). Individuals are expected to take care of their bodies and in this way become good citizens (Alftberg and Hansson 2012; Armstrong 1995; Rose and Novas 2005). Therefore, self-care is considered a moral precept in developed countries. Rapid modernization in China also fosters this new form of morality, which is not only a response to social changes, but also a coping mechanism to oppressive conditions. Unlike Western societies where biopolitics either acts upon populations or individuals, in China, it is directly related to the functions of families. According to the legislation, adult children are supposed to take care of senior parents. However, as I discussed above, this family function is on the decline, and the over-emphasis on this function often results in moral controversies. Therefore, the emergence of self-care in China is more about an individual moral strategy to deal with the decline of family functions than a cultural and social transformation, although there might be some overlap.

Emphasizing self-care in China as a moral strategy to deal with the limited family function of eldercare opens another question regarding individuals' willingness to accept self-care as a new moral code. In this chapter, I argue that "the generation in the middle"—who realizes that family members are not reliable for the future eldercare—has ambivalent feelings about self-care as a new form of morality. Their responses range from grudging acceptance to ambivalence, and then, finally enthusiasm, depending on individual contexts.

Some spousal caregivers were forced to accept self-care after they realized that their children were failing to fulfill their care obligations. They had to equip themselves with the new form of morality when their children were not willing to or unavailable to provide care and support. Mr. Liu (#W02) had been taking care of his 90-year-old wife for about twenty years. Although this couple had five daughters, they all either migrated out of China or lived very far away. Liu lamented that the contemporary society "force[d] us to live alone and provide self-care because nothing good comes from living with your children." The intergenerational tensions regarding eldercare have been well recognized by many family caregivers. Mrs. Jiang (#042) was taking care of her husband who had mild cognitive impairment. This couple had two sons, both married with their own careers. Due to family disputes, their oldest son stopped contacting them ten years ago. Although the senior couple maintained a harmonious relationship with their youngest son, considering the potential conflicts, Mrs. Jiang relinquished the expectation of adult-child care. She said:

> I have told my husband that we will not depend on our children. We have our own pensions. We are in our seventies, and cannot do what we want in this age. The society does not allow us to depend on our children, so we will care for ourselves. It is just hard to accept that we have to continue to eat bitterness late in life.

Adult children's lack of moral responsibility forced spousal caregivers to give up the expectation of adult-child care. However, taking care of oneself late in life is not a desired outcome, particularly considering that "the generation in the middle" has already endured life-long hardships. No matter how brave these family caregivers used to be, they were vulnerable and "cannot do what they want in this age." Therefore, being reconciled to self-care becomes a moral strategy to solve intergenerational conflicts.

The uncertain future and the increasing vulnerability of one's old age also complicates adult-child caregivers' attitudes toward self-care as a new form of morality. Scholars have documented strategies that Chinese parents adopted to ensure late life support, such as preferring daughter caregivers (Shi 2017c), investing in daughters' education (Zhang 2009), and helping taking care of grandchildren (Yan 2016). Indeed, these strategies to some extent can ensure life support; however, the future remains bleak for those parents who have one child or no child. Mrs. Shen (#056) was in her sixties, divorced, and childless. She was taking care of her mother with her siblings. When I asked about her plan for future eldercare, she felt ambivalent about self-care since "this was a choice that I[she] had to choose, regardless of having a child." In our conversation, I learned that she was a sent-down youth during the Cultural Revolution, and later, in order to return to Shanghai, she divorced her husband. Since then, she devoted all her efforts and time to her career development and never got married. Since Shen made more money than her siblings, she financially supported them to raise the younger generations. Originally she thought these relatives might take care of her in late life. However, she gave up this fantasy after a dispute with one of her nieces. She explained her attitude as following:

> No matter how much you devote to your children, they are still not reliable for eldercare. My siblings have to take care both of the grandchildren and our mother, and sometimes they have to financially support their children. Even so, they might not receive good care from their children. We all have to rely on ourselves.

Unlike spousal caregivers who already reached an old age, these adult-child caregivers are typical of "the generation in the middle," who take care of both parents and grandchildren. Many family caregivers in this condition often complained to me, saying that "you will never understand our feelings of self-care"—feelings, in other words, being abandoned by their adult children.

While acknowledging that some adult children don't feel the moral responsibility to take care of their parents, not all members of the younger generations feel this way. Actually, everybody in China feels the increasing competitiveness as a results of rapid modernization. Many seniors often show sympathy for the younger generation by self-care or taking care of grandchildren. Mrs. Shao (#004) was taking care of her mother, and her husband took care of their only granddaughter from Monday to Friday. Sometimes the senior couple had to take care of their granddaughter during weekends when the young couple had to work or study. Mrs. Shao stated: "Unlike our generation, we stayed in a state-owned company, and there was no need for additional work. Now, the younger generations have to work extra hours. I totally understand they could not take care of us. That's why I often tell my husband that we should take care of ourselves to reduce the burden on our son." The case of Shao exemplifies the function of the family in contemporary China. On the one hand, "the generation in the middle" have to continue to contribute to the whole family by taking care of both the young and the old; on the other hand, they are enthusiastic to take care of themselves to reduce the potential burden on the working age generation. Embracing self-care becomes a compromise strategy to ensure family solidarity.

Some seniors even embrace self-care as a moral strategy to liberate the younger ones from care duties. Mrs. Liu (#037), who took care of both her 93-year-old mother and her granddaughter, lamented that eldercare was neither productive nor meaningful when care receivers completely lost functions. She expressed that quality of life was more important than life span. Mrs. Liu explained: “After taking care of my mother, I know how challenging it is for a family caregiver. I have told my daughter that I will take care of myself. If someday I am in an emergency situation, I do not want any treatment; I want to die soon to liberate her from such a burden.” Self-care emerging in this context is invoked as a moral code that one should follow. Although embracing self-care, the fear of being a burden compels Mrs. Liu to adopt strategies—such as giving up any treatment or dying prematurely—to liberate her daughter from the burden of care. Otherwise, she might feel guilty of becoming a burden to her daughter.

Arguing that eldercare is neither meaningful nor productive stems from the logic of capitalism. Self-care as a moral strategy is consistent to this logic. An individual should not expect child-based eldercare if he or she fails to give property to one’s child(ren). Mr. Gan’s (#082) embrace of self-care as a moral practice dramatizes this reality. He was a sent-down youth in Gansu province for almost thirty years. Like many sent-down youth, he returned to Shanghai after he retired. Without a place to live, he stayed with his parents and took care of them for more than twenty years. Unlike many family caregivers who had accumulated certain wealth during the economic reform, Mr. Gan ended up having nothing except his small pension, which barely supported him. When I asked about his future, he sighed heavily and said he did not deserve any care from his daughter since he had no money left for her. Because of his poor economic condition, he classified himself as a “secondary citizen” in Shanghai. From his perspective, eldercare has become something that one needs to negotiate with adult children. “I should take care of myself. My life is like the sunset. It’s almost over and I should not drag her down,” said Mr. Gan. As China becomes more capitalist, eldercare is portrayed as an unproductive labor that consumes unnecessary social resources. Correspondingly, it might not be desirable to live into old age. As the state struggles to develop effective social support for seniors, self-care becomes a toxic solution to deal with population aging.

Self-care in China arises as a coping strategy to deal with the limited family functions of eldercare and oppressive state power. It has not been fully embraced as a cultural norm due to the underdeveloped social services. Meanwhile, self-care generates new controversies since it often involves the balance between individual prosperity and family solidarity. People born during the collective era often feel they have been manipulated by the state, since their needs such as eldercare are excluded or unable to keep up with the speed of modernization. Ignoring seniors’ contributions to both families and society as a whole not only discredits their social status, but also undermines the family culture in China. Families or domestic settings become an exploitative labor regime and a source of moral controversies due to conflicting values. This situation will continue to exist during China’s modernization process. In the following section, I will discuss how “the generation in the middle” revitalize old forms of morality to make sense of their care practices even though there might be a bleak future for their own eldercare.

The Revival of Old Forms of Morality

Along with the entrenchment of the secular values and the state’s sanction of capitalist ideology is the notable revival of traditional beliefs in the post-reform era. These beliefs, including Confucianism, Buddhism, and Christianity, provide a spiritual space for family caregivers to make sense of their care practices. Although the influence of Christianity on China is relatively new compared to Confucianism and Buddhism, I consider Christianity as an old form of morality in terms of its long history in Western societies. In this section, I argue that these old forms of morality serve as strategies for "the generation in the middle" to solve moral dilemmas, and offer them opportunities to develop moral agents.

Confucianism

During the past century, Confucianism has been severely attacked by various sociopolitical movements in China; however, some core values—such as filial piety and conscience—have remained guiding principles for moral agents. Scholars (Shea et al. 2020) have documented that filial piety has been modified to reconcile moral dilemmas related to eldercare in East Asia. One significant shift in filial piety is from an older patriarchal order to a more recent order that focuses on responsibility (see Chapter 4). Despite this, it is generally accepted as a moral aspiration to be a good person. In Shanghai, some adult children try whatever they can to take care of their parents. For example, Mr. Qiu (#008), aged 29, had been taking care of his mother for three years. Four years ago, his father was diagnosed with cancer and died shortly after. His mother was later diagnosed with lung cancer and underwent surgery and chemotherapy; then she was diagnosed with dementia. "There were always sadness in my family in these years. I had no mood to talk to people around. After knowing my mother's diagnosis, my girlfriend broke up with me," said Mr. Qiu. His brother, who worked in the Silicon Valley and had financially supported him, suggested Qiu consider getting married first.

Qiu was in no mood to do so. When I learned that he quit his high-salary job in order to take care of his mother, I said he was a filial son. Yet, he sighed and explained that:

> I do not think I am morally "high, big, and up (*gao da shang*)." She is my mother, and I am her son, and we are family. If I do not take care of her, who would? People around also say that my mother might be a good mother when she was young. Actually, it was my father who took care of my brother and me. I did not feel her special mother love, and she never bought us clothes. But, now, my father has died, it's my responsibility to take care of her. That's it.

The sense of responsibility becomes a symbolic indicator of filial piety in contemporary China. Taking responsibility means assuming duties, and also refers to one's attitudes toward the needs of family members, particularly when they are ill. Therefore, the sense of responsibility is closely related to one's moral status. As a young man at a working age, Qiu gave up his job to take care of his mother because he felt his moral responsibility. By taking care of his mother, Qiu not only fulfilled his duties, but also crafted his morality, i.e., his sense of self as a responsible person. Regardless of legal regulation, people have to follow certain moral codes by carrying out specific actions to justify their moral status. Otherwise, they fail to be moral agents. Unlike Qiu who could quit his job by relying on his brother, most adult children at the working age do not have such a luxury because they have to engage in economic activities. In a highly competitive society, people often feel they have limited time to provide eldercare, even though they have such an awareness.

It is not uncommon for some adult-child caregivers, especially those who are the only-child, to quit their jobs when senior parents are in need of intensive care. However, that does not mean they do not have work concerns. Ms. Kang's (#040) case was typical. Like Qiu, she quit her job at the age of 28 to take care of her mother because her father died twenty years earlier, and Kang was the only child. Although Kang was willing to take care of her mother, she also expressed concerns about work. In order to solve her work-care conflict, she started an online shopping store, which did not require strict work hours. Kang said: "I know my life has changed a lot since my mother got sick. Now I have to deal with all the care tasks and household chores. I have no choice even though my career has changed for the worse. I have only one mother, and I have to take responsibility for her."

Conscience is another core value that has been frequently mentioned by "the generation in the middle." Conscience, or *liangxin*, which literally means a good or virtuous "heart/mind," is a quality of those individuals who remember their moral obligations and try to act on them (Oxfeld 2017). Unlike filial piety which emphasizes the "outer" side of Confucianism (e.g., behavioral guidance), conscience pays attention to the "inner" side (Berling 1996). An adult child who shows filial piety to his/her parents is a person with a good conscience. By abiding the behavioral guidance, he/she becomes a moral exemplar. On the contrary, one without *liangxin* or with a troubled conscience is a person who often forgets his/her moral debt, which displays the inferior morality of the person. Therefore, both the "outside" behaviors and the "inside" inspirations are critical for an individual to establish good conscience.

Without a reward, care practices often derive from caregivers' conscience. Mrs. Wang (#100) had been taking care of her mother for almost ten years. She was fully aware that she had to go to a nursing home for eldercare in the future since her only daughter was abroad. Even so, she provided genuine care to her mother. Wang explained that: "Raising children for my mother's generation was for old age support. Because of their expectation, my conscience does not allow me to send her into a nursing home. Otherwise, I would be regretful after my mother dies." Likewise, Mrs. Lv (#062) provided care for her mother "based on conscience." She felt she had a good conscience because of her patience and love:

> My mother cannot understand now, but I can. She raised four children through her whole life. When we were kids and could not understand, my mother taught us and she never complained about our misbehaviors. It's the opposite when children take care of their parents. They often complain that their parents are stupid and crazy, and treat them harshly. I do not behave in this way.

The aspiration for achieving a good conscience and the adverse effects of a troubled conscience, e.g., guilt, are important factors that inspire family caregivers to continue their family-based care. According to Confucianism, the meaning of having a good conscience is directly related to one's moral status, whether he/she is a good and caring person. Worthy of special attention is that the motivation of performing conscience is different from traditional practice. Traditionally, one's good conscience is achieved through his/her awareness of moral debts and acts of reciprocity accordingly. Echoing Yan's (2003b) remarks about eldercare in rural Northeast China, an individual's practice of conscience largely depends on whether parents treat him/her equally in inheritance rights or other benefits. In the above two cases, Mrs. Wang and Mrs. Lv both received property from their mothers as a prerequisite condition to perform eldercare. To some extent, they chose to fulfill care obligation when receiving benefits from their parents. Their emphasis on conscience distinguishes their behaviors from those who simply target on parents' property without taking good care of them.

Like filial piety that has been modified, the interpretation of conscience is also contextualized. An extreme case I encountered during my fieldwork was a daughter caregiver who treated her mother and father so differently but never felt a troubled conscience. While Mrs. Pan (#011) took good care for her mother with dementia, she paid almost no attention to her father, who had a cholangiocarcinoma. The reason was that her mother used to take care of Pan and her siblings but her father always went against Pan and barely contributed to her business. According to Pan's conscience principles, good people should have good rewards. Since her mother was a good person, Pan paid more attention to her mother's condition than to her father's. After her mother was diagnosed with dementia, she spent a lot of time to find the best physician for treatment. She even went to a fortune-teller for help, who told her that her mother's illness would become better after her father died. Mrs. Pan said: "If I have to choose one from my parents, I will choose my mother." This extreme case might not be representative; however, it demonstrates a contextualized condition of pursuing conscience. On the one hand, people show their sincere love and care toward those who used to treat them well; and on the other hand, people become even more ignorant and uncompassionate when dealing with resentment. Compared to the traditional form of conscience that emphasizes being generous toward all people, the modified conscience becomes negotiable and contextualized in contemporary China.

Buddhism

Religious beliefs are not only to provide guidelines to solve moral dilemmas, but also to reduce the affliction of human suffering. Karma is a key concept of Buddhism, which illustrates that every action has a consequence that go beyond a human lifetime. When someone commits an evil act, they acquire karma; when one does good, he/she acquires merits, and eventually it will cancel out karma. The unique interpretation of doing goodness has transformed the way of dealing with moral dilemmas during caregiving.

Some family caregivers believe that taking good care of senior parents is to receive blessings from Buddha. Mrs. Huang (#W31) took care of her ninety-year-old mother. Unlike her siblings who often complained about the challenges of living with their mother, Mrs. Huang happily moved her mother into her own apartment. Moreover, when most family caregivers lamented about the care burden, she felt grateful for taking care of her mother. These seemly uncommon behaviors derived from her belief of Buddhism. Since she married, she and her husband converted to Buddhism. Mrs. Huang considered that Buddha had blessed her family a lot, including her daughter's overseas education, work, and marriage. She also expressed that seniors represented the family prosperity. "My mother is a treasure. If we have a senior parent in our family, indeed, she will generate more blessings for us. If you mistreat her, you will receive retribution," said Mrs. Huang. When I asked her about the potential for this couple to go to nursing homes for eldercare, Mrs. Huang felt that Buddha would continue bless them in that case.

In addition to guiding people's daily behaviors, Buddhism serves as a technique to make sense of family disputes. Mr. Zhang (#064) and his senior brother take care of their father in turn. They were supposed to share half-and-half of their father's housing property. Disputes happened after the senior brother took all of the property and left nothing to Mr. Zhang. Mr. Zhang could not solve this struggle and later developed severe alcoholism. His wife, who was a Buddhist, tried her best to persuade her husband to let this frustration go. Yet, it did not work since her husband was hospitalized several times due to severe drunkenness. In order to relieve the suffering from her husband, Mrs. Zhang even tried to persuade the senior brother to give 300,000 RMB [$42,000 USD]—a large amount of money from her personal savings—to deceive her husband that he received his property. However, the senior brother did not even care about this suggestion. Mrs. Zhang felt that she had done everything she could do to solve the disputes. Since then, she had replaced the two brothers to take care of her father-in-law, without receiving any benefits. When I interviewed her, she was in a peaceful mind and expressed her point of view:

> We do not want to have disputes with any family members. Now it happens to us. I think that taking care of our farther [father-in-law] is our responsibility. Buddha knows that I am doing mine, and you do yours. Property is not something that you can fight for. If it is yours, it will eventually be yours. If you get the property that does not belong to you, retribution will happen someday. I believe what goes around comes around. I have told my husband to let it go, but he cannot.

The application of Buddhism in everyday situations demonstrates the wisdom of "the generation in the middle" to solve moral dilemmas. Rather than fighting the injustice that happened to them, Mrs. Zhang turned to Buddha to justify her resignation— "what goes around comes around." In order to solve the intensive brother relationship, she offered her brother-in-law a huge amount of money, even though she was declined. When she realized that a secular solution was not possible, she tried to persuade her husband to "let it go." She even replaced her husband to take care of her father-in-law. Family disputes certainly disrupted their life, but the ways Mrs. Zhang solved them provided an opportunity—albeit a difficult and bitter one from outsiders' perspective—to reach a spiritually high ground that brought her a kind of inner peace.

Buddhism also helps family caregivers seek alternative ways of treatment, particularly when dementia sufferers' health conditions getting worse. Mrs. Xu (#084) had been a Buddhist for more than thirty years. Originally she was a volunteer of a local temple. Her experience of healing her breast pain through chanting Buddhist scriptures reinforced her belief in 2010. After that, she showed piety to all the people around. When she was a nursing aide in a hospital, she witnessed the mistreatment of elders by some aides. Mrs. Xu tried to comfort these elders and then told the aides to do good deeds to accumulate both wealth and merits. After she retired in 2013, she started to take care of her mother. Unlike other professionals who only turned to biomedicine for help, Mrs. Xu—even with professional experience of caregiving—sought both religious and biomedical strategies to deal with her mother's illness. In 2014 after her mother developed a severe stroke, Mrs. Xu immediately sent her mother to a hospital. The doctor told her that her mother's chance of survival was small since she was in a coma. After learning that, Mrs. Xu called her Buddhist teacher to perform rituals and chant for her mother. After three days of religious and biomedical efforts, her mother gradually recovered. Mrs. Xu stated the following:

> Buddhism is amazing. People who do not believe it would feel that we have a blind faith. After you experienced the healing power of Buddha, nothing can challenge your belief. I now recite Buddhist scriptures for more than three hours every day. Everything in my family goes well. My mother's health condition gets better. My years of diabetes have also been cured.

The spiritual effects of Buddhism to some extent can transform itself to a healing power. In this study, I am not arguing the biological healing mechanism of Buddhism. Rather, what we have seen is that religious practices offer alternative chances for people to negotiate with their sufferings, particularly when biomedicine or scientific explanations fail to do so. Mrs. Xu's case demonstrates that when family caregivers could not manipulate biomedicine's outcome, what they could do was to turn to religion. Religious practices offer an opportunity not only to realize one's Buddhist expectations, but also to solve moral dilemmas, such as the boundary of one's care obligations. Moreover, turning to religious power of healing does not mean that people completely give up their faith in biomedicine. Mrs. Xu used to be a nursing aide and had medical knowledge, which means that she knew the limitations of biomedicine. Even knowing the limitations, Xu believed that biomedicine deserved a try. The combination of biomedicine and religious practices corresponds to the local ethics—care as stewardship in Chapter 5—in which family caregivers actively engage in biomedicine and modern technology to negotiate health outcomes. Accordingly, pursuing Buddhism and following its instructions during care practices becomes an avenue for family caregivers to craft their spiritual morality.

Christianity

Like Buddhism, Christianity guides individual behaviors during everyday care practice, such as praying, doing good, and seeking the spiritual peace. More importantly, its institutional structure—the church or group gathering—establishes a new form of social support, which becomes urgent when formal support is limited. Since family caregivers have suffered various hardships during their life time, spiritual support offers a chance for them not only to make meaning of their past experiences, but also to cultivate their moral characters.

Mrs. Yuan (#W32) links her suffering with Jesus's calling, in particular, her responsibility for taking care of her parents assigned by God. Before she took care of her parents— one suffering from dementia and the other having severe glaucoma—Yuan had two failed marriages. Although she married twice, Yuan was poor in terms of maintaining an independent living. In addition, her son quit high school without a job. What made things more complicated was that Yuan's father married with her mother when she was a widow with four children. In other words, before Yuan was born, her mother had already had four children, and Yuan was the only child her parents biologically had. Because of the complex relationships, family conflicts surrounding eldercare and property inheritance often happened. When I met Yuan in an extremely hot summer afternoon, she was reading the Bible in her parents' room. A large picture of Jesus was hung on the wall, with the Chinese letter "Jesus is Love." She told me that she converted to Christianity in 2010 after her second failed marriage. At that time, she almost committed suicide. Her aunt introduced her to the church and gradually she went out of the shadow of suffering. Yuan shared with me how Christianity changed her attitude toward caregiving:

> I attended [church events] several times and each time I was touched by the Spirit. When I cried, friends around me would say my sufferings were borne by Jesus. After several times, I got baptized. No matter how busy I am, I attend the church worship each week. Jesus guides me to show love and care to my parents. My [half-blood] brothers and sisters all have their homes and families. I am alone in this world. That’s why Jesus chose me to care for my parents. I am fulfilling my care obligations assigned by God and Jesus is with me.

While acknowledging that Christianity has transformed sufferings into meaningful spiritual experiences, we should note functions of the church in contemporary China. For most believers, church is not only a spiritual shelter, but also a social space for one to express her needs and receive support when society fails to do so. Instead of being a source of support, Mrs. Yuan’s parents, her son, and her siblings became multiple burdens when her own life encountered difficulties. Compared to social sufferings, hardships created by family members are more challenging because of moral controversies. Often, these family issues are considered as private concerns that outsiders should not interfere. Yet, Christianity provides a space where one could talk about these issues and one’s vulnerability is valued and supported—a significant support that is scarce in the secular world.

Christianity often becomes the only source of support when one is in a desperate situation. Mrs. Chao (#W15) has been a Christian for more than ten years. I had known her for a long time since we often met in the church. Occasionally, I visited her and her mother in their home. Mrs. Chao had been a sent-down youth in Mongolia for almost twenty years. Before she returned to Shanghai, she was divorced by her husband and her work unit was bankrupt at that time. Yet, she and her son eventually returned to Shanghai in 1999. When recalling this period, she often attributed their life changes to her Christian brothers' and sisters' day-and-night prayers and visits. "It was a poor place, but for our own sake, Christians all came over to help, and my son eventually received an offer from a college in Shanghai after he failed the initial review," said Chao.

This form of support becomes even more urgent when Chao returned to Shanghai. Like many sent-down youth, Chao could not find an official job because of her hukou was still in Mongolia. Again, it was her Christian brothers and sisters in Mongolia that helped to process the hukou transfer to Shanghai. In 2002, her father was paralyzed after a severe stroke, then, her mother was diagnosed with dementia in 2009. Hardships came one after another; yet, Chao always turned to her church friends to help. According to Chao, they would pray together and sometimes considered fasting. "God's power is made perfect in your weakness. When I am suffering, I know God's power will unfold in my life," said Chao. With such a strong belief, she survived one suffering after another. Eventually, her son graduated and found a high salary job. He also bought a new apartment so that Chao could live with him. Unlike other spoiled adult children, her son constantly gave Chao money and helped her to take care of grandparents. In 2016, after almost fourteen years of caregiving, her father died. Since then, Chao and her two brothers took turns to take care of their mother. In 2017 when I conducted my fieldwork, I learned that Chao and her mother had moved out of the neighborhood. After several phone contacts, we decided to meet in the church where we used to attend. During the gathering, she gave a public testimony:

> Without so many [Christian] brothers' and sisters' help, I could not see God's glory in my life. God has given me blessings and sufferings, depending on whether you surrender yourself. Once you obey, then, you receive God's blessing. Suffering produces perseverance; perseverance produces character; and character produces hope. This is what I think.

Suffering offers an opportunity to examine the roles of traditional beliefs in bringing spiritual transformation. Traditional Chinese philosophers have well recognized suffering and its meanings. According to Mencius, a significant Confucian philosopher, one's will and persistence will not reach to a perfect status without enough suffering. Therefore, suffering is an essential experience of cultivating one's morality, which aims to enable him/her to shoulder greater responsibility. However, suffering from religious perspective has a different interpretation. Buddhism often explains suffering with the concept of karma—a person's suffering is related to one's bad deeds, and therefore, by doing good, one relieves the suffering. While Christianity also has the functions of cultivating one's morality and guiding one's behaviors, it goes beyond these secular meanings. In Christianity, suffering offers an opportunity to witness the love and power of God. In order to achieve the divine purpose, believers often pray together and support each other in difficulties. Therefore, Christian support is twofold—social and spiritual meanings.

While acknowledging that traditional beliefs have played an important role in bring inner peace, strength, and even hope to people in suffering, we should note the underdeveloped social services in China. In my conversations with "the generation in the middle," family caregivers without specific beliefs often lamented the challenges of taking care of dementia sufferers. According to their perspective, hardships in one's late-life stage make one even more vulnerable to bear the care burden, which often affects one's inner strength. Without effective social support for family caregivers, religious beliefs become a mediator to regulate the state-society relationship and the relationship between suffering and meaning.

Conclusion

This chapter has demonstrated the moral encounter during family caregiving—the ascendency of moral dilemmas and simultaneously, the noticeable revival of traditional beliefs as well as a new form of morality flourishing among "the generation in the middle." I have discussed two types of moral dilemmas in Shanghai—the unclear boundary between family's responsibility for taking care of elders and caregivers' potential benefits, and the misuse of collectivism among the older generation and individualism among the younger generation. The legislation of family's responsibility serves as both cultural and political regimes to uphold the capitalist goal of economic development by sacrificing "the generation in the middle." Likewise, the ideology of collectivism becomes a disciplinary tool to maximize the productivity of family in terms of taking care of both the old and the young, while caregivers' personal benefits are overlooked. It is the discrepancy between the political goal and individual aspiration of certain form of morality that has created these dilemmas. By teasing out relationships between capitalist economy, state power, family solidarity, and individual prosperity through a grounded examination, this study also identifies a new form of morality (e.g., self-care) and the revival of traditional beliefs (e.g., Confucianism, Buddhism, and Christianity) among family caregivers. These forms of morality provide both implications for the governance of life and the working mechanism of making moral agents.

First, this chapter brings family caregivers' moral orientations into dialogue with the emergent form of self-care in China, which theorizes the new form of morality as a response to perplexing social changes, or a coping mechanism under oppressive conditions. Family caregivers endorsing self-care—from grudgingly acceptance to completely embrace—mediates the tensions between state-enforced family-based eldercare and the "caregiving crisis" (Jesmin et al. 2011), and between the family solidarity and individual prosperity. Self-care serves the neoliberal goal of both economic development and the establishment of a new moral standard. It does not necessarily imply a cultural transformation by completely dissolving moral dilemmas. I argue it creates new moral dilemmas since family caregivers endorsing self-care are to strengthen family functions, no matter for the sake of their adult children or individual benefits. Likewise, endorsing self-care does not imply that Chinese society is becoming more individualized. Rather, I argue that self-care, together with the old forms of morality, suggests a more hybrid mode of local moral system. Therefore, it is better to understand self-care as a temporary and dynamic form of morality through which eldercare is shaped by the existing social and political structure.

Second, this chapter illuminates that the revival of traditional beliefs is better theorized as an imaginary morality that constitutes the strategies to deal with moral dilemmas. No matter modified Confucianism, Buddhism, or Christianity, these forms of beliefs provide caregivers with symbolic, cultural, spiritual, and social resources to negotiate their disadvantaged conditions. By engaging in various forms of traditional beliefs, family caregivers transform the suffering experience to meaningful ways of being. For example, family caregivers' interpretation of conscience and their understanding of the relationships between suffering and blessing illustrates how a person is actually located in the economic, kinship, community, and work activities that defines one's moral characters. The question on these traditional beliefs is not simply about spiritual transcendence but rather how each belief is implicated in the process of crafting moral agents. This process is situated to the secular modernity and capitalist economy as well as individual beliefs.

Third, regardless of self-care or traditional beliefs, these forms of morality are not only alternative strategies to solve dilemmas and craft moral agents, but also techniques to resist the political structure that favors capitalist economy. No matter how nonpolitical these strategies seem, family caregivers' activities of seeking inner peace, pursuing meaning through suffering, and crafting a good conscience, are to some extent counteract the transition toward lived experience based on capitalism and individualism. Ironically, due to the limitation, these activities obfuscate and even re-legitimize the state power in terms of mandating family's responsibility for taking care of elders.

Overall, this chapter has argued that sociopolitical transformation in China has created moral dilemmas during family dementia caregiving. Self-care and traditional beliefs serve as alternative strategies for family caregivers to solve these dilemmas. Endorsing these forms of morality does not necessarily transform Chinese society from a morally divided one to an integrated one. Rather, they inform us how family caregivers, especially “the generation in the middle,” respond to the perplexing social changes, or a coping mechanism to the oppressive conditions.

Conclusion: Politics, Practices, and Morality of Dementia Care

Several changes have been made to improve dementia care in Shanghai. In January 2018, one month after I finished my fieldwork, the long-term care insurance started to cover all residents in Shanghai, with the hope of providing social support for older adults who were in need of intensive care. In the same year, the government official, Mr. Chen Yuebing, who was in charge of social services for elders, promoted the concept of shared gerontechnology in neighborhoods of Shanghai. According to some news reports, family caregivers can rent these technologies with a lower price than that on the market. Meanwhile, Mr. Chen actively promoted the project of building dementia-friendly communities in Shanghai. The number of these communities had expanded from one initial trial site in 2018 to about ten in 2019. All of these changes are inspiring that the landscape of dementia care is improving in China.

While acknowledging these forms of social support are necessary and important to relieve the burden on family caregivers, most tasks of dementia care are still domestic. In contrast to older Chinese living in institutional settings—who often experience alienation, social and physical distancing from their age peers, or potentially mistreatment (Dong et al. 2008; Wang et al. 2018; Zhang 2017c)—family caregivers try whichever methods to keep their kin at home in Shanghai. With the aid of modern technology and social media such as WeChat, family caregivers share their experiences and struggles with other caregivers online. Questions often include: pros and cons of drugs, behavior management, memory training, and more importantly, caregivers' own health issues. Many problems that cannot be effectively solved by conventional care or social services seem to find alternative solutions from modern technology and medicine. While on the surface, one might take this as painting a rosy picture of dementia care in Shanghai, family caregivers, like their compatriots elsewhere in China, are by no means insulated from stresses from the overwhelming care burden.

The dementia care burden is closely related to rapid social changes, which shape different modes of care. Aulino (2019) suggests that modes of care are closely related to the forms of social organization. For instance, in Thailand, embodied routines of caregiving are habituated actions, reflecting the unique religious, social, and political structures. Building upon Aulino's thesis, this project further demonstrates that rapid social changes equally shape certain forms of care, and different care paradigms may conflict with each other when stakeholders put them into practice. Take the debate of medical care for dementia sufferers in Shanghai, for instance. Historically, psychiatrists were the main service providers for dementia patients. However, the development of modern technology, e.g., the visual technology that can identify the neuropathological changes in the brain, legitimizes the authoritative status of neurologists. As a result, neurologists negotiate dementia conditions as a neurodegenerative disease rather than a mental disorder. Their activities, including changing medical training curriculum, establishing academic research associations, engaging in community-based health education, aim to establish and reinforce their authoritative status to treat dementia. The debates about the classification of dementia in China exemplify how a biomedical concept can be changed by and demonstrate certain forms of biopolitical power.

The construction of dementia care as historically contingent on myriad factors justifies the potential conflicts between different modes of care. Previously, when dementia was classified as a mental disorder by psychiatrists in China, there was a severe stigma associated with this condition. The public portrayed people living with dementia as those with aggressive behavior and violent tendency, and this group of people should be physically constrained to maintain the social order. Yet, due to limited public health education, no treatment, and the potential stigma, most Chinese family caregivers did not consider mild dementia symptoms such as memory decline in old age as a disease (Ikels 1998). Correspondingly, family caregivers took the majority of dementia care, and social services for dementia sufferers in China were underdeveloped. The reconceptualization of dementia as a neurodegenerative disease, however, brings new challenges to the organization of social services for dementia sufferers. This classification aims to reduce the potential stigma and the aggressive-amiable dichotomy by emphasizing the degenerative nature of this illness. The availability of potential treatments that may improve dementia conditions also changes the public understanding of this illness. Compared to the previous understanding, two decades later after Ikel's (1998) study of dementia care in Guangzhou, most Chinese believe that dementia is a disease that can be prevented and treated to some extent. Accordingly, people living with dementia, even with aggressive symptoms, should be treated by humanistic care and professional services. Both state and non-state actors devote time and efforts to promote social services for this group of people, e.g., dementia-care units, dementia-friendly communities, and person-centered care. Although these Western notions of dementia care are good and important for dementia sufferers, the introduction of these notions in China challenges the previous moral framework of dementia care. As a result, conflicts between the old and new frameworks of care become intense. What constitutes "good" dementia care, how it should be practiced, whose authority is accountable, and how to balance individual and collective benefits, are several debates among various stakeholders when certain forms of care are putting into practice.

These conflicts disturb us sensorially by placing dementia care practices front and center, which are closely related to power structures and cultural understandings. The historical examination of the changing conceptualizations of dementia in China demonstrates the interaction between state officials and medical professionals as well as the interrelationship between biomedical and ethnomedical professionals. Medicalizing dementia as a stigmatized mental disorder is embedded in the social and historical context of a devalued person in Chinese culture. Such biopower is organized through state ideologies in governing human bodies and formulated by medical professionals in producing a form of knowledge to serve political goals. Likewise, the professionalization of dementia care services is to enable China enter into a rank of modern nations based on humanity. Cultural understandings of appropriate social services for dementia sufferers not only complicate the power structures in promoting certain forms of care, but also intensify the uncertainty, distress, and insecurity when different care paradigms actually interface with each other in practice. When the state promotes the systematic care model by institutionalizing dementia sufferers, non-state actors, especially nursing home directors, exercise their agency to endorse relational care and integrate Western humanitarian ethics with Confucian values. By doing so, non-state actors mobilize a different ethical code that is culturally appropriate but often ignored by the state. However, in practice, inappropriate regulations of the state officials often place additional anxieties and distresses on nursing home directors. For example, rapid policy changes without taking the experience of nursing aides into consideration creates uncertainty of institutional care. To solve these conflicts requires both state and non-state actors to craft, adjust, and remodify these policies.

Conflicts between different modes of care in China demonstrate both what matters in care practice and about the social world in which these conflicts occur. Because the majority of Chinese elders continue to maintain expectations of family care, even in the face of economic and social changes that have occurred in Chinese society over the past four decades, there is a resistance to institutional care among some older adults. Chen (2016) suggests that Chinese elders who have enrolled in nursing homes are mainly for the purpose of liberating their adult children from the care burden, rather than willingly embracing institutional care as a way of life. The bitterness of lack of family care is also recorded by Traphagan (2000) in his study of Japanese older adults. This study reinforces these findings. Because family affection is still valuable for seniors, eldercare institutions have to take it into consideration for better dementia care. Aulino (2019) suggests that framing caregiving situations is rife with pitfalls, because what is justified on one aspect is often contradicted on another. The reconfiguration of Western humanistic care and Confucian values indeed reveals a great deal about the formation of care and how this process is linked bodily practices with the broad social and political context.

The emphasis on the social configuration of dementia care also brings attention to how different factors shape familial forms of care. Ranging from family politics on care arrangement to the decision-making process of institutionalization of senior kin, familial care is influenced by rapid social changes in China. Take care arrangement for instance. Previously, Chinese family was dominated by the patriarchal order in which young, inferior, females were caregivers. Rapid modernization and social transformation has challenged this patriarchal family order into various forms. As described in Chapter 4, there is a hierarchy of potential primary caregivers: spouses first, adult children second, and paid care third. Senior spouses become caregivers for their partners due to the fact of the unavailability and/or unwillingness of adult children to get involved in care practice. Moreover, some adult children negotiate with their parents regarding housing property and care obligation. Along with the transforming patriarchal family order is the flexible gender roles within domestic settings. This study has shown an increasing number of male caregivers. Both sons and husbands have to get involved in caregiving because of the lack of female caregivers and women's withdrawal from traditional gender roles. The flexible gender roles and the negotiable relationship between generations offer the opportunity to achieve the egalitarian familism. Liu (2017) argues that individuals in contemporary China are no longer living for the continuation of the family or family needs; rather, it is the family structure that constantly changes to fit the needs of individuals. Building upon Liu's argument, this study further demonstrates that both individuals and family structures have to mutually adjust to meet both individual and family needs. Various degrees of individual adjustment have created different forms of family structures to meet the needs of dementia sufferers, and vice versa.

Examination of the day-to-day care practice by family caregivers can provide a needed platform for different care paradigms to unfold, taking into consideration not just political and social stances but all that is embodied in care practices as well. I found that family caregivers in Shanghai respond to the increasing care burden in multiple ways. Care as stewardship and resigned familism are two alternatives to traditional family-based care that emphasizes filial piety and hands-on practices. Within the stewardship paradigm, family caregivers who have accumulated both knowledge and social resources are more easily to equip with modern technology and medicine to improve care outcomes. Yet, family caregivers who suffer from negative association with dementia (e.g., stigma) and the deprivation of social support are more likely to endorse resigned familism. It is necessary to associate these two forms of care with biopolitical discourse, yet insufficient, for making sense of the changing field of dementia care in China. Bourdieu's (1990) practice theory, which take both objective and subjective aspects into account, is instructive to analyze field, capital, and habitus associated with dementia care. The coming age of modern technology, e.g., gerontechnology, will enlarge the social disparity in terms of access to this benefit, which will in turn complicate the burden discourse of dementia care. I have shown embodied ways of being—the folk understanding of dementia and care, family estrangement, and inadequate social support—that have habituated family caregivers to resigned familism. Rather than abhorrently condemning the structure and oppressive power, this project takes in to account the ways that people are complicit with these coordinates (e.g., either using or giving up modern technology) in their everyday practice of care.

Despite of multiple ways of responding to the care burden, family caregivers search meanings of through care practice, as when individual efforts cannot generate desired outcomes. Problematic meanings such as karma are all too easily reinforced in Buddhist culture (Aulino 2019), and some family caregivers in China resonate with this cultural interpretation (Chapter 6). In addition to the religious meanings, new meanings are emerging among family caregivers, ranging from enjoying conjugal love at late life stage to seeking transformations of the "old" relationships. These meanings are not merely held in propositional commitments. Rather, family caregivers often have to coordinate with the reality, such as the incurable of dementia and the limits of one’s financial, emotional, and physical capacity to provide care. As dementia progresses, family caregivers have to seek social support to maintain the previous care arrangement or seek alternative ways of care. The trajectories of care are closely related to family resources, notions of “good” care, and the accountability of social services. Each transition requires family caregivers to recalibrate their obligations and rights, benefits for dementia sufferers and potential harms, and pros and cons of other modes of care. During this process, seeking meanings of dementia and care becomes more desperate for family caregivers. Their narratives (Chapters 5, 7, and 8) remind us that a family’s search for better care can have exorbitant monetary and emotional costs. Without effective support from both domestic settings and society, family caregivers often have to shoulder this burden alone. This highlights the need for policy makers to rethink seriously how dementia care and social support should be conceived and delivered.

Family caregiving provides important insights into the dynamics of family-based care and the sustained social change at large. In particular, the habituated practices of care for people living with dementia underscores the Confucian values such as filial piety and familism. However, this habituated practice is tightly linked with rapid social changes in China, from demographic to cultural. Due to the One-Child policy, there will be less and less family members available and willing to provide such care for ill kin in China. The fact that family caregivers provide care for their senior parents without a guarantee to receive care from their children at late life stage intensifies the moral dilemma of these caregivers. In an economic-centered society, boundaries between family responsibility for eldercare and caregivers' rights and between individual benefits and collective ones are often not clear. The legislation of family responsibility for eldercare serves as both cultural and political regimes to uphold the capitalist goal of economic development by sacrificing "the generation in the middle." Likewise, the ideology of collectivism becomes a disciplinary tool to maximize the productivity of family in terms of taking care of both the old and the young, while caregivers' personal needs are overlooked. What makes matters worse is that there is a lack of recognition of family caregivers' contribution to the family and society. The popularity of the new form of morality (e.g., self-care) and the revival of traditional beliefs imply both the governance of life and working mechanism of politics in a rapidly changing society.

My analysis of the moral dilemmas of family dementia caregivers highlights the limits of morality within Chinese society about the role of Confucian values in sustaining traditional family-based care. I have unpacked power structures, social advancement, and cultural habitus to reveal the possibility of family engagement in providing care. In a country with the largest size of older population, family caregiving is no longer a domestic issue. Providing care for older adults and supporting family caregivers at increasingly social levels entails perceptual changes and service modifications that are predicated on particular social, cultural, and political parameters. Traditional family caregiving based on filial piety will not run in a long term, because the overwhelming burden does not dissolve. The burden discourses of dementia care include stigma, helplessness, family estrangement, and lack of social support. Family caregivers talk either explicitly or implicitly about caring for their kin, family, and society at large, and how limits of their physical, emotional, and spiritual capacity to carry on care as kinship practice I have traced in this study.

The meaning and experiences of dementia and care in China, as in any society, is not simply a matter of biological changes that occur as the result of a pathological condition. It is equally a matter of sociocultural changes that are subject to the political ambition of building a nation based on science and humanitarian care for its citizens. The debates of scientific knowledge of dementia and professional services for dementia sufferers should be understood as historically contingent events during the process of modernization in China. Dementia matters in China also because of the associated care primarily relied upon family caregivers, and experiences of people living with dementia are tied closely to their family caregivers. Thus, understanding practices and moral experiences of family caregivers is a prism through which to study key issues surrounding contemporary Chinese culture and society, such as governance of life, organization of services, dynamics of social norms, and mixed feelings toward modernization.

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