

# Ethnography of Eldercare by Elders in Shanghai, China

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**Abstract** While existing media and policy discourse on aging and caregiving in China is dominated by attention to the burden of elder dependency, this article provides an ethnographic glimpse of the under-recognized role of older adults in providing informal care to the elderly in Chinese society today. The analysis is based on a quantitative survey and ethnographic fieldwork involving participant observation and interviews conducted in a residential area of Shanghai Municipality, the Chinese city with the highest degree of population aging in the nation. Conducted between 2010 and 2014, our research examined whether and how older adults in Shanghai can be considered as not just persons in need of care but also as active contributors of eldercare. While we observed senior aid to the aged occurring both within and outside family households in Shanghai, in this article we focus on elder caregiving within the context of the family, with particular attention to caregiving provided by elders' spouses. Overall, we found that patterns of eldercare in Shanghai today are much more complex than public discourses dominated by the elder dependency concept might lead one to believe. Our study found that many older adult women and men in Shanghai are making significant contributions to eldercare in the form of both spousal mutual aid and spousal primary caregiving. We further found several ways in which the identification of a primary caregiver can be quite complicated in a methodological sense, whether in quantitative or qualitative research. We conclude that more careful scholarly and policy attention to older adults' contributions is needed to better understand and address the challenges and potentials of China's aging society.

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## Introduction

With many developed and some developing countries today experiencing an unprecedented rise in the age of their populations, concern has arisen about the effects of this demographic change on the welfare of those nations (United Nations and Social Affairs 2013). In response, much existing scholarly, policy, and media discourse on those aging societies is focused on the burden posed by so many elderly citizens. Sometimes dramatized as an oncoming “shock of gray” (Fishman 2010) or the “threat of the silver tsunami” (Schumpeter 2010), narratives on population aging today are often premised upon the assumption that older adults are largely unproductive, unhealthy, and dependent upon young and middle-aged adults for their support and care.

China is among those nations undergoing a rapid increase in the age profile of its citizenry. In China, where 60 years of age is the traditional threshold to old age and the official retirement age is generally age 60 or younger, statistics on the elderly population are commonly pegged to that benchmark, mirroring frequent WHO (2015) practice. In those terms, while only 7.2 % of China’s population was age 60 or older in 1980, in just under three decades the proportion had already almost doubled to 12.0 % by 2009 (Banister et al. 2009: 8) and has more than doubled to 16.1 % by 2016 (Beijing Daily 2016). It is further expected to reach 31 % by 2050 (Banister et al. 2009: 8), rivaling the levels currently reached by Japan, the world’s national forerunner in population aging.<sup>1</sup>

Despite traditionally priding itself on having a culture that values longevity and upholds respect and care for the aged (Ikels 2004; Fan 2007; Zhang 2009), Chinese public discourse also commonly contains themes of concern about the burdens of an aging society. Chinese commentators remark that the Chinese nation is currently facing an aging population “problem,” “difficulty,” “crisis,” or “hazard.” They point with alarm to the population’s growing “old-age support ratio,” defined in many Chinese sources as the proportion of people age 60 or older per every 100 members of the “working-age population” (Fang 2012).<sup>2</sup> Such sources note that by 2012, the old-age support ratio in China had reached 19.7 % or only “five young working-age people to support every one elderly retired person” (Fang 2012). They argue that these challenges are of an unprecedented scale, because unlike aging societies in the developed world, China has “gotten old before getting rich,” thus heightening the threat of an old and thus dependent population on the welfare of the nation (Gao 2009). While sometimes recognizing that older adults have, do, and/or will continue to make contributions to society, their focus is on the possible negative effects of population aging on the nation, society, and economy (Han 2012) and particularly on the “young working-age” population (Fang 2012). In such discourse, age is associated with being unhealthy,

<sup>1</sup> To peg this to the age 65 benchmark with which many readers will be more familiar, while 8 % of China’s population was aged 65 and older in 1980, in just a little over two decades the proportion had nearly doubled to 14.5 % in 2012, and it is expected to reach 30 % by 2030 (Gao 2010:18).

<sup>2</sup> In order to match western sources, sometimes Chinese commentators also use the alternative international benchmark of age 65 to calculate the old-age support ratio, in which instances the ratio is of those age 65 and older compared to those age 15–64 (United Nations and Social Affairs 2013: 25).

unproductive, dependent, and burdensome, while youth are assumed to encompass their opposite.

Along these same lines, as in many other nations, recent national policies on aging in China (e.g., Central Committee of the Chinese Communist Party (CCCCP) and the State Council 2000; 2006; 2011; Standing Committee of the National People's Congress of the People's Republic of China 2013; State Council of the People's Republic of China 2006, 2011, 2013, 2016) have been focused on the needs and rights of the aged and on the role of the young in meeting them, with only a little attention given to seniors' societal contributions. The crux of these policies center on rising to the challenge of meeting the needs of the increasing number of adults age sixty and older, as well as on the moral duty to do so. They assert that seniors in China have a right to material and instrumental support (老有所养), to health care (老有所医), to leisure and happiness (老有所乐), to continuing education (老有所学), to teach others (老有所教), and to participate in and contribute to society (老有所为). While government, community, business, and nonprofits are allotted some role, the main responsibility for meeting elders' needs is placed on family, stating that ninety percent of the elderly should be cared for by family at home. This expectation is made explicit in the national 90-6-4 policy and the Shanghai 90-7-3 policy, both corresponding to targets for the percentage of elderly persons to be cared for by family at home, in community-run care, or in institutional care, respectively. In line with the widespread social narrative mourning a modern decline in Confucian filial piety (Cheung and Kwan 2009), these policies appeal to the "virtues of traditional Chinese morality" of "respecting, supporting, and assisting the elderly" (中华民族敬老、养老、助老的美德). In doing so, they focus on adult sons and daughters as bearing primarily responsibility for meeting elders' needs, followed by adult children-in-law, thus adopting a gender-neutral stance not found in the original Confucian practice, which expected eldercare from sons and daughters-in-law and not from daughters and sons-in-law. The duty of spouses, along with siblings, to take care of each other is included in some policy documents, but receives very little attention. When contributions of seniors to society are mentioned, the focus tends to be on elders' right to participate in society, rather than on the social utility of their doing so, and the young-old (under age 80) are specified. While there is mention here and there of the role of the young-old in local senior associations and senior mutual aid and of the contribution of young-old experts in sharing knowledge with distant impoverished regions, the everyday informal non-skilled contributions of seniors across the old-age spectrum to family and neighbors receive little attention.

While there is truth to the crisis and dependency model of aging societies and there is value in stimulating society to protect those seniors who are vulnerable, global scholarship in gerontology warns us that such pessimistic angles on aging are only part of the picture. Such scholarship points out that modern aging societies not only enjoy the blessings of longevity, but that serious impairment is often delayed, allowing for many active and productive later years (Hooymann and Kiyak 2011). In addition, this research points out that while not formally tabulated like wage labor and the GDP, informal labor in family and community is worth a great deal to both human wellbeing and the functioning of society (AARP 2011). Such gerontologists point out that by shifting focus, we see that not only do older folks have needs, but they also make large contributions to society even when they not performing wage labor (O'Reilly and Caro 1995). Anthropological approaches to gerontological research further stress the

importance of attending to the perspectives of older persons themselves, taking a holistic view on social reciprocity within and across the generations, and using a life history perspective to get beyond snapshots in time (Sokolovsky 2009). Such scholars point out that giving and receiving support and care in later life are not necessarily mutually exclusive; rather the give-and-take of social life in old age is often multi-directional, complex and fluid.

One of the ways in which older adults internationally have been found to make a large contribution to society in the informal sector is in family caregiving, and a key aspect of this is caregiving for the elderly. In the US, for example, recent studies have shown that familial caregiving for the aged in America is often provided by older adults, with the average age of family eldercare providers nearly 60 years of age (NAC 2009: 15). Recent studies have also found that spousal caregiving is a particularly prominent modality for eldercare in the US (Bourgeois 2012; Braun et al. 2009; NAC 2009; Newcomer et al. 2012), surpassing that of eldercare done by adult children and nursing home facilities. In contrast to the dominant discourses referenced earlier, recent studies have also shown that eldercare contributions by older adults in the US are not limited to those individuals with no significant health problems. For example, the Administration on Aging (2004) has found that many older caregivers providing care for elderly family members in America do so while managing chronic conditions and impairments of their own. Therefore, it is important to consider the ways in which older adults are not just burdens with needs to be satisfied by the young, but are also active contributors to their own care, even in the face of significant health challenges.

Recent academic surveys conducted in China have also begun to show the growing importance of eldercare by elders in Chinese society, including seniors' spouses. The 2015 China Survey on the Development of the Family is a prime example. This survey enrolled a national sample of 32,494 households comprising 184,439 individuals from rural and urban areas of 31 provinces (Beijing Evening Beijing Evening 2015; NHFPC 2015; Wang 2015). Emerging reports on the survey results have revealed several ways in which older adults are pivotal in eldercare in China today. First, the study found that most elderly people in China today rely on either themselves and/or their children for support and care. The rising importance of self-care was attributed mainly to increases in healthy longevity and/or labor migration of adult children. Second, the survey found that half of all elderly people in China now live in "empty-nest households," including about forty percent of seniors living with just their spouse, and ten percent living alone in a single-person household. As a consequence, in contrast to the traditional ideal of adult-child eldercare associated with intergenerational cohabitation, spousal caregiving is becoming increasingly important in both urban and rural areas of China. Finally, the study found that almost a third of seniors in China undertook some paid work in 2013, thus participating in not only informal domestic, but also formal wage labor. With regard to rural elders, the survey showed that almost a quarter have been left behind by children migrating elsewhere for work, and a large number are living in skipped-generation households, caring for their grandchildren on behalf of their children. All in all, the national survey shows that many older adults are taking on important productive roles in contemporary Chinese society.

Some recent regional studies supplement the above national findings to address the relative incidence of eldercare by spouses compared to adult children, as well as recent patterns in the gendering of care by adult children. For example, a 2010

survey of 2950 adults age 60 and older in Zhejiang Province found that in both urban and rural areas, the number-one type of family caregiver for the elderly was spouses (Senior Daily 2011). In urban areas of Zhejiang, next in line after spouse were daughters, followed by hired home helpers, then sons, and finally daughters-in-law. In rural areas of Zhejiang, however, while spouses were still first, the gendering of care by adult children was more traditional than in the urban sample. In rural Zhejiang, next after spouse was son, then daughter-in-law, then daughter, and, finally, hired help. A 2014 survey in the municipality of Tianjin on a random sample of 880 households with at least one adult age 60 or older delivered findings that resemble those of urban Zhejiang. That Tianjin study found that seniors with dementia were mostly likely to be cared for by spouses (35.48 %) and daughters (38.16 %), followed by sons (33.27 %) (Baoshan Zhengdian 2015). In addition, this report also pointed out that beyond the spousal caregivers being elderly, the majority of the daughters and sons providing such caregiving were either over age 60 or in their fifties and thus “nearly elderly.” Others scholars like Hua and Di (2002) have observed more broadly that elderly spousal caregivers provide a large share of the direct care given to sick and disabled seniors in China today. While precise figures on the gendering of spousal eldercare were not reported for these studies, the reports indicate that both elderly husbands and wives were involved in such care.

In the pages that follow, we turn to original data that we collected in Shanghai to examine the role of older adults in elder care there, with particular attention to the role of elders’ spouses. Shanghai is currently the Chinese city housing the nation’s oldest population. By 2015, Shanghai had a population of 4.36 million adults over the age of sixty, comprising 30.2 % of the city’s total population (Xinhua 2016). This is about the same percentage that China as a whole is expected to have by 2050. In this sense, Shanghai is a city for which scholars and policymakers have argued that we may be able to catch a glimpse of China’s future eldercare situation.

From 2010 to 2014 the authors of this article collected a mixture of quantitative and qualitative data related to home-based eldercare in a residential area of Shanghai. In examining this data in light of the issues discussed above, our overall research questions are as follows: In quantitative terms, are older adults identifying as primary caregivers to an elderly person living at home? Are spouses of home-dwelling elderly identifying as their primary caregivers? What are their proportions relative to younger folks and non-spouses identifying as primary caregivers therein? In qualitative terms, for spousal caregivers engaged in home-based eldercare for frail or ailing seniors in Shanghai, what are some of their situations like? Why are they, rather than their children, taking primary care of their husbands or wives, and how do they feel about it? Based on our quantitative data, we argue that older adults and spouses are indeed identifying as primary caregivers for home-dwelling elderly, although at a somewhat lower rate than middle-aged and younger adults and adult children. In addressing the higher proportion of the latter, we caution, however, that one must not assume that such self-identification always objectively reflects relative degree of engagement in eldercare tasks. Stemming from our qualitative data, we argue that many factors besides un-filiality on the part of adult children contribute to spouses serving as primary caregiver for their spouse. Although the work of caregiving can be difficult, for a variety of reasons, many spouses of the elderly take pride in being a primary caregiver for their

husband or wife. At the same time, however, for several spouses who initially identified as primary caregivers, over time it became clear to the researcher that a large amount of spousal mutual aid was occurring or that relative roles of spouses changed over time.

## Methods

This ethnographic study employed mixed methods of data collection and analysis. Data collection consisted of a quantitative community-based survey on eldercare patterns in a Shanghai residential area, along with qualitative interviews and participant observation on the role of Chinese seniors in eldercare in that same area. Use of these methods together afforded the ability to examine the distribution of self-reported in-home primary care provision in the community and to explore the grassroots social ecology of and local meanings behind the many ways in which Chinese seniors themselves are contributing to eldercare in their families and communities. In order to plumb grassroots views and behavior, we place special emphasis on the qualitative data we collected.

The quantitative community-based survey was conducted in 2010 on caregivers providing in-home care to elders who were living in and around the lower-middle-income downtown Shanghai neighborhoods where the qualitative research would later be carried out. The survey aimed to gauge the household caregiving situation of caregivers providing care to elders who were physically frail or had dementia. Respondents were drawn from a sample of 8 neighborhood “residency committees” (居委会) out of a total of 19 such territorial subdivisions within one Shanghai “street committee” (街道) which is a geographic unit below the level of an urban “district” (区). Veteran volunteers from a local non-governmental organization (NGO) were trained in survey technique and went from door to door in the community to households known by local residency committee workers to have an ailing elderly person living at home receiving caregiving assistance. At each of these households, the surveyors asked that the primary caregiver (主要照料者) in the household fill out the survey. Thirty caregivers were sampled from each of the eight neighborhood residency committees under study, resulting in a total of 240 self-identified primary caregivers taking care of an elderly person who was living at home. The survey was not exhaustive of all households with elders receiving caregiving at home, however, it gives us a general idea of some of the most important kinds of elder caregivers in the community. In addition to their self-identification as a primary caregiver, respondents were asked about their age, their relationship to the elderly care recipient, the amount of time they spent on caregiving, and disease categories of care recipients. The resulting data was entered into a database and checked for accuracy. The quantitative data was then used to compile basic descriptive statistics on family-based eldercare in the local community.

Our qualitative fieldwork, which was conducted between 2012 and 2014, focused on developing an in-depth understanding of the community context for aging in place in and around the Shanghai communities covered by the survey described above. Data collection methods included participant observation, informal conversation, and semi-structured interviewing focused on the eldercare needs and contributions of neighborhood seniors in community context. Participant observation included walking the neighborhood streets, alleys and nearby parks and visiting local residency committees, eldercare service NGOs, community senior associations, and adult day-care centers. In these contexts, we had the opportunity to engage in informal conversation and participant observation with a variety

of local residency committee cadres, social service professionals, and neighborhood volunteer retirees over the course of several years of visits. We also visited numerous private family homes between 2012 and 2014, talking with in-home elder caregivers of all ages, including both adult children and spousal caregivers. Family caregivers were recruited through ties to local NGOs and local residency committees which had detailed knowledge of home-based informal caregiving for frail elders. Special attention was placed on visiting and interviewing the important but oft-neglected category of spousal caregivers over the age of sixty. As such, audio-recorded home visits were made to 30 spousal caregivers between their sixties and nineties in 2012, with follow-up visits to most of those respondents in the summers of 2013 and/or 2014. These spousal caregivers were identified by local NGO volunteers who had been going to their homes to visit them regularly for over a year or more. Caregivers were screened by volunteer report and caregiver self-report to meet the following criteria: The caregiver was at least age sixty, currently caregiving for their spouse at home, had done so for at least 3 years, identified as a “primary caregiver” for their spouse (主要照料者), and reported doing more of the work than anyone else in providing care for their spouse. Based on volunteer and caregiver self-report, care recipients were screened along the following dimensions: at least 55 years of age, currently unable to care for themselves independently (不能自理), required caregiving due to a chronic illness, needed caregiving only after the age of fifty, and needed assistance with at least two activities of daily living such as eating, personal hygiene, dressing, toileting, or moving around. In addition, they were screened to be of Han Chinese ethnicity, lower middle to middle income level, and having lived in this location for at least 3 years. In the process of screening, several other couples were also visited. Detailed fieldnotes were taken on all participant observations and informal conversations, and semi-structured interviews were audio-recorded with permission and then transcribed verbatim in Chinese characters. Analysis was conducted through the open and axial coding methods of the grounded theory form of qualitative data analysis (Strauss and Corbin 1990). Translation was aided by the co-authors’ complementary native and secondary language capabilities in Chinese and English. To protect confidentiality, each caregiver and their spouse was given a pseudonymous surname. In accordance with Chinese tradition, husbands and wives were assigned different surnames, and following local practice, the fictive kinship terms Grandma, Grandpa, Aunt, or Uncle were added, with the former for those aged 80 and up and the latter for those younger than 80.

## Findings from Shanghai Community Survey on Home-Based Eldercare

In examining social patterns of eldercare for aging in place, we begin with our findings from the 2010 community-based quantitative survey on home-based eldercare in Shanghai. This survey provides a glimpse into the distribution of the types of people who self-reported as primary caregivers for ailing seniors living at home in the neighborhoods in and around where our qualitative research took place. In addition, the resulting sample does well to mirror the range of caregiving intensity and common health conditions affecting the aged in China overall. Households surveyed spanned the gamut of in-home eldercare intensity from light to extensive need for assistance. In addition, the sample mirrored the top causes of disability and death in China with recipients’ main conditions including heart disease, stroke, respiratory disease, arthritis, dementia, diabetes, blindness, cancer, and Parkinson’s.

## The Factor of Age

In analyzing this data, we found a large contrast with national policy and media emphases on the dependence of the older population on the young. Examining the factor of age, we found that many of the caregivers responding to the survey were elderly themselves. Out of the total of 240 caregiver respondents, caregiver age ranged from 21 to 92 years of age. More than four out of every ten caregiver respondents were age 60 or older (42.5 %). As may be expected, of the 102 elderly caregivers surveyed, young-old caregivers were more common than old-old caregivers, with 79.4 % aged 60–79 and 20.6 % aged 80–92 years of age. Of the total sample, about five out of every ten caregivers were middle aged, falling within the 40–59 year old age range (53.3 %), with most of those in their mid- to late fifties. Mirroring results found for the US, overall the average and modal age of the caregiver respondents was in the late fifties, a category sometimes referred to in western gerontological literature “nearly old.” In this case, the average caregiver age was 59.4 years of age, and the mode was 56.5 years of age, ages which are commonly considered “old” or “nearly old” in China as well, especially given that retirement or job loss before the age of sixty there is fairly common. Less than five percent were young adults (4.17 %), and there was just one single caregiver in their twenties. Clearly, older adults form an important part of the home-based caregiving situation in this community.

## Relation to Care Recipient

In examining the social relation of caregiver respondents to eldercare recipients, we found that the overwhelming policy and media emphasis on the traditional role of adult children in in-home eldercare underestimates the experiences of a very important player: spouses. Our survey results showed that spouses of eldercare recipients were identified as a key backbone of in-home elder care for seniors aging in place, alongside adult children. While, taken together, about half of the respondents identifying as primary caregivers were adult sons (26.5 %) or daughters (24.7 %), spousal primary caregivers also made up a sizable proportion at over one-fifth of the respondents (21.8 %). Although respondents who were adult sons or daughters were more common, our qualitative findings give us several reasons to believe that their objective role in eldercare may be overestimated, as will be outlined in the discussion that follows the results section of this report.

With regard to the gender of those identifying as primary caregivers, the results revealed a gendering of caregiving responsibility along lines commonly found in other studies internationally, but also showed an important difference in gender patterns between spousal and child-to-parent care. Reflecting the common overrepresentation of females in shouldering eldercare, the data showed that 63 % of the primary caregivers surveyed were female and 37 % were male. However, among primary caregivers who were adult children, there was a roughly equal number of respondents who were adult sons (26.5 %) and daughters (24.7 %). The main gender difference in primary caregiving for the elderly was found in the spousal caregivers. While both husbands and wives were represented, wives were much more likely than husbands to be primary caregivers. This makes sense given that Chinese men tend to marry women who are younger than they are, and Chinese women tend to live longer and to be more active later in life than Chinese men.



With regard to children-in-law, like many other studies conducted in contemporary China over the past few decades, we found that the traditional Chinese pattern that privileged the role of daughters-in-law as eldercare proxies for adult sons was very weak in this community. The percentage of respondents who were daughters-in-law was very low (5.9 %). In addition to social change in intergenerational gender roles, part of this very low representation by daughters-in-law as primary caregivers may relate to Shanghai's more muted patrilineal tradition and stronger parent-daughter ties as compared with northern China. Never traditionally obliged to care for their in-laws, sons-in-law had very low representation as family eldercare providers in our survey with less than two percent of respondents (1.3 %) claiming this relation to the ailing household elder.

Other kin identifying as primary caregivers for home-dwelling seniors included siblings of the elderly (1.7 %) and grandchildren (1.3 %), who made up about the same proportion of respondents as sons-in-law. While some of the siblings were only "nearly old," some were well over the age of sixty. It is interesting that despite their advanced age, siblings were more common caregivers than grandchildren, making collateral kinship ties a bit stronger than extended lineal ties. Our qualitative fieldwork showed that this is because while siblings are often already retired, grandchildren are regarded as needing to focus on study and career.

Beyond the family, primary caregivers for ailing elders who were neighbors (4.2 %) were almost as common as daughters-in-law. Friends (1.3 %) of eldercare recipients reported being their primary caregivers at about the same rate as sons-in-law. Most often neighbors and friends who took on this role in the sample were old or nearly old themselves. In addition, there was a miscellaneous category of other (11.3 %), most of whom were hired help, indicating the further heterogeneity of in-home caregivers, involving non-kin as caregivers, as well as growing commercialization of care.

### **Extent of Caregiving Involvement**

Whatever their relation to the eldercare recipient, the involvement of these respondents tended to be quite substantial. About three quarters of the caregivers lived with the recipient (74.8 %), and about one fifth lived very close (19.3 %). Over half of the respondents spent an average of 7 or more hours per day taking care of the care recipient (60.3 %). Most others spent either 4–6 hours per day (15.1 %) or 1–3 hours per day (22.2 %) in elder care. The majority had been caring for the elderly care recipient for a long time, with almost half having spent 6 or more years doing so (49.0 %), and most of the rest having spent 1–5 years thus engaged (43.1 %). Most caregivers said that their care recipient could not function without them, rating their care recipient on a range from severe (28.3 %), to moderate (33.3 %), to light (29.5 %) dependence. Caregivers over the age of sixty and spouses of eldercare recipients tended to spend even more time doing eldercare tasks than younger respondents.

### **Findings from Qualitative Research on Spousal Mutual Aid and Primary Care**

It may help to begin by clarifying how the characteristics of our qualitative sample differed from our community survey sample described previously. Beyond only

sampling spousal caregivers over the age of sixty, the qualitative sample differed from the community survey in that the care recipients therein all had at least a moderate level of impairment when we first visited households in 2012. Mirroring the community survey, however, the kinds of health conditions suffered by the care recipients were very similar, including dementia, cardiovascular disease, stroke-related paralysis, respiratory disease, arthritis, osteoporosis, diabetes, kidney disease, cancer, and Parkinson's.

To begin the analysis of these qualitative findings on spousal caregiving in Shanghai, it must be said that we employed a purposive sampling strategy designed to identify cases that, by definition, went against the notion of senior dependence found in public discourse on the crisis of an aging society. After all, we were seeking out situations in which elderly spouses were primary caregivers, that is, the old were taking core responsibility for caring for the old, and spouses were taking a larger role than adult children. In addition, we purposively sampled not just young-old (age 60–79), but also spousal caregivers over the age of eighty, with just under half of our sample (13 out of 30) caregivers being old-old (age 80+), with the oldest clocking 92 years of age in 2012. Although this sampling was by design, such cases were not hard to find in the neighborhoods where we focused our research. Not anticipated in the generalizations of media and policy, in a few cases the older spouse was taking care of the younger spouse; in these cases, generally the husband was caring for the wife as most Chinese men tend to marry women several years younger than they are. Due to deliberate sampling, we had an equal number of husband and wife primary caregivers, although male spousal caregivers are less common as age advances due to their shorter average longevity compared to women. At the same time, it was not difficult to find the fifteen men needed to round out the sample.

Other kinds of non-alignments between the assumptions surrounding the notion of elder dependency did not, however, directly flow from our qualitative sampling strategy. For example, the majority of the spousal caregivers in the qualitative sample had one or more chronic disease or impairment of their own, such as high blood pressure, obesity, arthritis, chronic headaches, hearing impairment, or old work-related injuries, but they nonetheless shouldered the main responsibility of care for their spouse. Merely looking at statistics related to health conditions would not indicate that they were the “healthy” kind of “young-old” people able to care for others mentioned in policy documents.

While three of the 30 Shanghai spousal caregivers interviewed in our study expressed some resentment about their fate, none of them reported feeling that they were stuck holding the bag because their children were unfilial. Rather, they felt that their children were “filial,” but busy with their own lives. Most of the spousal primary caregivers were living separately from their children, making it inconvenient to ask for much instrumental help from them, and even those who lived with their children were nonetheless the ones who did most of the work assisting their spouses with activities of daily living. The latter occurred both because their spouse felt more comfortable with them helping with these intimate tasks, and because most of the young and middle-aged adult children had other things that they needed to do, such as work. Even some of the young-old adult children who were beyond retirement age could not offer much help, because their finances were shaky due to early retirements or layoffs, leading them to be preoccupied with trying to carefully manage their money and/or make extra money through post-retirement odd jobs. Many young-old adult children were also busy doing

cooking and housework for their children and/or taking care of their grandchildren. For most of the seniors we interviewed, asking for help from adult children was something done very selectively. They did not want their neediness to take away from all the investment that they had made to get their children and grandchildren to where they were now with education, jobs, and/or finances. Economically, for elders to care for elders makes sense in China today, because younger people's time is often seen by younger and older folks alike as better spent in self-cultivation, education, remunerative work, and striving to improve status and social connections. Elderly parents in China have usually invested a great deal in striving to make a better life for the younger generation, so they are reluctant to work at cross-purposes by diverting too much of their children's or grandchildren's labor into their later life care. As a consequence, many seniors in China with some means would rather make do by themselves, whenever and however they could.

In addition, many spousal caregivers interviewed took certain forms of satisfaction from their ability to take care of themselves and their spouse. For example, instead of speaking in the language of needs and rights and entitlement and guarding against greedy children, interviewees tended to speak of fulfilling responsibilities, contributing to family and society, and being satisfied with what they had. For the generations of elders interviewed, Spartan collectivist socialization during the Maoist period (1949–1976) was layered on top of older Confucian norms of sacrificing to cultivate the next generation, thus generating a widespread tendency for today's elderly mainland Chinese parents to scrimp and save to try to protect their adult children from parental expenses. There was also great pride about saving enough to lend adult children or grandchildren money for education, marriage, and/or housing. While monetary transfers from children to seniors are still very materially important in many poor rural areas of China, this is often not the case in urban areas today, where many seniors have pensions, elder subsidies, and health insurance coverage, reducing their need to depend on their children for support.

Rather than seeing seniors as replete with needs, all of the caregivers interviewed emphasized that they and their spouse did not need much and that they were much more easily satisfied than youth as they had grown up through hard times. The caregivers tended to emphasize that they did not need or want money or help from their adult children, that they had their own money, and that they did not want to take something away from their children or grandchildren. There was a lot of pride in making do on their own and not asking for much. When asked about whether they could use some assistance with housekeeping from hired help, most said that they would not trust hired help because they were outsider migrants who might steal something or who would not know how to do a good job or keep things clean enough. Very few of those we interviewed expressed interest in community-based services, and many said that they would much rather be given more money instead so that they could buy whatever they needed themselves. Reflecting the tumultuous history of their younger years and their generational socialization, all of our interviewees felt that things were much better now than in the past in a material sense and that, for the most part, the government had done and was doing a lot of good things for the elderly and society.

Most of the spousal caregiver research participants tended to see their pensions, old age subsidies, senior discounts, and health insurance coverage as something that they and their spouse had earned through the work that they had done when they were

younger, in their jobs and in building up the developing nation. Thus, rather than feeling dependent on governmental support, they felt glad that they had a government that was recognizing the contributions that they had made to the nation's growth over time. To them, the pensions that they had earned were what allowed them to be independent from their children. Being residents of Shanghai, our study participants were more fortunate than many rural dwellers in China, for which the 2015 China Survey on the Development of the Family discussed in the introduction to this article found more than half must work in agricultural labor past age sixty. The fact that urban dwelling Shanghai seniors had a tendency to feel that old age support from their work units and the government were all something that they themselves had earned through struggle for work and nation over the course of their lives is a very important consideration that defies connotations of elder dependency ratio. Rather than seeing employer- and government-based old age support as a snapshot in time, a handout to those no longer formally employed, instead Shanghai seniors tended to take a longer view of delayed compensation for a life-time of work for employer and nation.

With regard to adult children, the seniors we interviewed saw their own children, including both sons and daughters, as a more important source of assistance than their daughters-in-law. However, going further than the national policies, some saw daughters and maternal ties as more important than sons and paternal ties. Like the urban Zhejiang and the Tianjin studies mentioned above in the introduction, many of those who had both sons and daughters remarked that they relied more on their daughters for help than they did on their sons. Like what Shi (2009) found in a northeastern Chinese village, many of the seniors we interviewed said that daughters were more emotionally close and thoughtful of their parents' needs (贴心, 细心). Some remarked that in Shanghai daughters have more power in a marriage and a closer relationship with their natal families than northerners do, so they can insist on helping out their parents and not just their parents-in-law. Similarly, they said that Shanghai grandmothers had more leeway to take care of their maternal grandchildren more than paternal grandchildren, if they so choose.

As mentioned before, early on in the qualitative portion of this research, all thirty of the spousal caregivers who received home visits and took part in interviews agreed that they were primary caregivers for their spouse (主要照料者). However, over time it became clear to the researchers that for several of the respondents, either a large amount of spousal mutual aid was occurring or the relative amount of care given and received between spouses changed over time. As a result, the findings below include accounts of both spousal mutual aid and spousal primary care. Beyond the thirty spousal caregivers who were followed over time, in the mutual aid section below we also include a few cases that received one screening interview but who were not subsequently followed over time as part of the sample of thirty caregivers due to it being clear from the start that it was more a case of balanced mutual aid than primary caregiving. For the other cases of mutual aid, it either became clear with more exposure to the couple, or things changed over time.

### Spousal Mutual Aid

In our fieldwork in the community, we observed many cases of spouses taking mutual care of each other (互相照顾) to one degree or another. In some cases, this involved an

imbalance in which one spouse was clearly the primary caregiver, but in other cases, there was a relative balance in the mutual aid exchanged between husbands and wives during the period of our research study. In cases of relatively balanced mutual aid and mutual reliance that were apparent at initial screening, there was no subsequent interview, and those cases were not included in the N of 30 spousal primary caregivers. However, among our sample of 30 spousal primary caregivers, there were three cases for which a relative balance in mutual aid became apparent over time. At initial screening, all those included in the sample of 30 spousal primary caregivers indicated that their spouse was unable to take care of themselves and was reliant on the caregiver for at least two activities of daily living. However, there were three cases in which a relative balance in mutual aid emerged with further observation or change over time. In the first of these three cases, balanced mutual aid became clear with deeper questioning and observation at the first post-screening interview. In the second case, the spousal dynamic morphed into balanced mutual aid as the health of the care recipient improved between the first and the second post-screening interview. Finally, in the third case, spousal mutual aid was spread out over time, such that one spouse was the primary caregiver at the time of the first post-screening interview, but roles switched as the spouses' respective health conditions changed over time.

Among the cases which did not go beyond initial screening, there were several cases of spouses who “made up for each other’s limitations” (互补) to the extent that neither would have been able to live independently without the help of the other, and both spouses relied on each other for help with at least two activities of daily living. In one of these cases, the residency committee knew that the husband was blind, and the wife was presented as the primary caregiver. In the other case, an NGO volunteer knew the wife to have dementia, and the husband was initially presented as the primary caregiver. In the first case, although Grandpa Pu was blind, Grandma Chu had her own health problems, including diabetes, obesity, and severe arthritis, which made it hard for her to get around. Yet, with each other’s help, they managed to live independently without aid from their children. The husband was spry and could run short errands around the house and in the neighborhood, both of which he knew well through experience. The wife, although largely housebound, had full use of her eyesight and could find and read things for the two of them. For their meals, Grandpa Pu could set up the rice cooker and go to a nearby food stall to get cooked meat and vegetables. Grandma Chu would spot their eating utensils and bathing materials and match their clothing, while her husband helped her with parts of washing and dressing that her arthritis made it hard to reach. In another such case, the wife, Grandma Wang, who had moderate dementia was initially presented as the care recipient, and her husband, Grandpa Chan, as the primary caregiver. However, it was quickly apparent at screening that they each relied on the other for many activities of daily living, as Grandpa Chan had developed substantial physical paralysis and weakness from a stroke. Nonetheless, they got along independently through the husband “providing the brain” and the wife “supplying the body.” Grandma Wang would prepare and cook dinner and feed, wash, and dress them both, but only with step-by-step instructions from Grandpa Chan. Grandma Wang also helped Grandpa Chan with transferring and toileting, but only with his detailed instructions. In both of these cases, neither spouse could have lived independently of outside help without the assistance of the other. If just one spouse were screened via questionnaire with the presumption that they were the primary caregiver, without first-

hand observation it would have been easy to miss the extent to which they relied on each other.

Other examples of mutual aid were included in the sample of thirty “primary” caregivers, either because their relative balance in reciprocal care was not evident until after the initial screening or because relative spousal roles changed over time. The first example is that of Grandpa Fu, age 89, and Grandma Tai, age 86, a case of spousal mutual aid that became clear with further observation. Initially at screening, the sense was that Grandpa Fu was the primary caregiver since he was very mobile and could run errands, whereas Grandma Tai had great difficulty getting around. Grandma Tai had severe osteoporosis and arthritis in her back and leg joints. She was hunch-backed and moved about their one-room ground-level apartment with great difficulty. Grandma Fu was tall, thin, lively, and fit, with a light step and a body that resembled a lanky teenage boy, with the addition of a lot of wrinkles. Grandpa Fu was often seen out and about in the neighborhood running errands, getting groceries, and taking walks. He helped Grandma Tai with dressing, bathing, and getting to doctor’s appointments. He also did most of the cooking, dish-washing, and laundry, as well as housekeeping like sweeping that required getting around. In addition, their daughter helped with some of the housekeeping when she came by to visit, but at least as of 2012 her help was just supplementary. Screening involved just a small number of short simple questions, and it appeared that Grandpa Fu was Grandma Tai’s primary caregiver. However, in talking at more length with them at the first post-screening interview, it became clear that Grandpa Fu was extremely deaf and needed Grandma Tai’s help in hearing things when a longer, more complex conversation was involved. As we talked, Grandma Tai would often repeat something that we said to him in a very loud clear voice as he leaned closer to hear and watched her face before he could make it out. Sometimes she would answer for him if she knew what he would say, and it was quicker that way. In addition, Grandma Tai was the prep cook and master of recipes for them. Grandpa Fu would bring her things, and she would sit at the table and de-string beans, shuck peas, peel vegetables, and assemble ingredients for Grandpa Fu to bring over to the stove to cook. Although Grandpa Fu did not technically need help to live independently if based on the ability to eat, bathe, dress, toilet, and move about on his own, his quality of life would have been quite diminished by his poor hearing and his inability to cook food that was not just edible but also tasty. Grandpa Fu and Grandma Tai were very proud that they could support themselves with their pensions and take care of themselves and each other, and, for the most part, not trouble their children. Both emphasized the need to appreciate and enjoy being alive, and they laughed a lot in each other’s company, providing each other with their most important source of social and emotional support.

The second example of spousal mutual aid which was included in the sample of 30 spousal primary caregivers was one involving change over time. At screening and first interview in 2012, Uncle Gui, age 78, was clearly the primary caregiver for Auntie Shu, age 74. However, by the second interview in 2013, the situation had changed into one of balanced mutual aid as Auntie Shu’s health had improved. When we first heard of Uncle Gui and Auntie Shu, the NGO volunteer presented him as the primary caregiver and initial screening and the first interview confirmed this sense. A few years before 2012, Auntie Shu had had a stroke, paralyzing her so that she was stuck in a bed in the hospital unable to talk. When she got out of the hospital, her left leg was extremely weak and unstable and her left arm was useless. She needed Uncle Gui to help her with

eating, washing, dressing, toileting, and transferring. Although he managed, Uncle Gui found nursing her at home, day and night, very challenging, because due to an accident at work more than a decade before, most of his fingers had been cut in half, leaving partial stumps, rather than full fingers. Although it took a long time, he did okay with helping Auntie Shu get her clothes on and washing the places that she could not reach. However, without full fingers, he found preparing food and cooking to be difficult and hazardous, especially in that Auntie Shu had been the main cook in all their earlier years. Although the couple felt that their children were filial, they did not want to bother them as they still needed to go to work. In addition, they felt that relying on buying relatively inexpensive food on the street was unhealthy. As a result, they decided to use some of their pension money to enroll in a community adult day care center. During the day, they got breakfast, lunch, and dinner there, so that they would not have to bother with those things themselves. At home, they only had to contend with dressing, bathing, and toileting, all of which were manageable. Meanwhile as time went on, Auntie Shu became steadier on her feet around the house and learned how to use just one hand to do more things. By 2013 Auntie Shu was using her good hand to help Uncle Gui with buttons and laces again, and Uncle Gui only needed to help steady her as they walked between their apartment and the day center. Uncle Gui felt that the caregiving he had done for his wife over the years after her stroke was a way to partially return the favor to her for the help that she had given him when he was first recovering from having cut off his fingers. The couple was happy to have found a way to stay independent by helping each other and using day-time community services so as not to have to lean on their children.<sup>3</sup>

The third instance of spousal primary care in the sample of thirty “primary” caregivers, was one in which the spouses also changed roles over time, but in this case involving a swapping of primary caregiver and care recipient roles as their respective health circumstances changed over time. When we first met in 2012, Grandma Huan, age, 82, had been the primary caregiver for her husband Grandpa Che, age 86, for many years since the time he had had a stroke. In the beginning, the stroke left Grandpa Che unable to speak and almost completely paralyzed on his whole left side. During the first year, Grandpa Che could not even sit up, and Grandma Huan needed to help him to dress, eat, bathe, and toilet in bed. In the years that followed, he slowly regained function. By 2012, he only needed some help with dressing and bathing some parts of his body due to continued weakness and stiffness in his left arm. By then he was able to eat on his own, though with some dribbling, and walk about on his own, although with a shuffling gait. His speech was still halting, but he could get his full message across. His left arm was still weak, but it could be used for tasks not requiring strength. Still, Grandma Huan did all of the cooking, cleaning, and housework so that her husband could mainly rest, relax, rehabilitate, and visit with his friends. When we met in 2012, Grandpa Che and Grandma Huan were both proud that they did not need to rely on their children for financial or instrumental help. Each of them emphasized that, as a retired Communist Party cadre, Grandpa Che was being taken care of by the Party, with

<sup>3</sup> In our qualitative sample of 30 spousal caregivers, there was one other case in which adult day care played a role. In that case, by his own admission the husband had never liked his wife, so he dropped her off at the community adult day center early each morning so that he could play mahjong with his friends until the day center closed just after they served his wife an early-bird dinner.

a large pension, 100 % of his medical expenses covered, and gifts from his work unit at the holidays. Together with Grandma Huan's more modest factory pension and partial medical benefits, they felt that they got along very nicely. Grandma Huan expressed satisfaction in being married to a man with so much more education and achievement than she had, and she felt proud to be able to contribute to making his retirement as nice as possible. However, a year later, their roles switched. Grandpa Che's left side continued to gain coordination and strength, while Grandma Huan came down with an unknown ailment that made the skin in her limbs and torso swell up so taut that the pain kept her moaning in bed. A community volunteer helped to arrange transportation to the doctor and to fetch medicine and groceries for them. Grandpa Che fixed simple food for the two of them and helped steady her on her way to the toilet with the use of his good right arm. In the end, however, doctors were not able to figure out what was wrong with Grandma Huan or to find a medication that would fix the problem. In 2014, she passed away, leaving Grandpa Che to fend for himself.

### Spousal Primary Care

Of the 30 caregivers sampled in our study, at the time of the first post-screening interview in 2012, 29 of them were clearly spousal primary caregivers able to take care of themselves on their own, with a spouse reliant on them for at least two activities of daily living. A solely questionnaire-based study that did not inquire about reciprocity between spouses or activities beyond the bare necessities of eating, bathing, dressing, toileting, and mobility would have registered the 30<sup>th</sup> respondent, Grandpa Fu, discussed earlier, as a primary caregiver as well. Based on our ethnographic observations and interviews, however, we categorized Grandpa Fu as a case of spousal mutual aid in 2012, and we found that two other cases had changed roles by 2013. This leaves 27 cases of spousal primary caregiving in which roles remained stable over time, until either the care recipient died or cases were lost to follow-up. Each of the remaining 27 cases represent a rich world of experiences, however, space limitations preclude in-depth discussion of all of these cases. As a result, in this section we will focus on detailed description of one case of spousal primary caregiving. Other cases will be described in future publications.

This case of a spousal primary caregiver brings together many of the central themes of this article concerning how elder dependence assumptions fail to account for many of the dynamics driving informal eldercare in Shanghai today. It also involves the very important issue of elders with dementia who act out with disruptive or violent behavior. As of the close of this study in 2014, there were still no facilities for this kind of patient in Shanghai. Other than home-based familial care, if such a patient could not be easily continuously sedated with medication and restrained in a nursing home facility, the only other options were a lock-down unit for the severely mentally ill or jail, both considered inappropriate by most families and institutional units. This is one of the areas of eldercare in most dire need of governmental investment, university research, and social entrepreneurial design.

We have also chosen this case because it shows how even when it would seem demographically that an elder would not be the primary caregiver for their spouse—they are over age 80, have multiple chronic diseases, and many adult children nearby—multiple factors can converge to produce that very result. In addition, it contextualizes



some of the complex cultural reasons that can lead to an elder with an extremely difficult caregiving burden not wanting much help from family or outsiders. It also shows how daughters and age peers are often preferred to sons for caregiving help and emotional support.

Grandma Zuo was 80, and her husband Grandpa Qian was 85 years old when we first met them in 2012. As a couple, they lived alone in a one-room apartment in a crowded maze of narrow alleys in downtown Shanghai, where we visited their home three times in 2012 and once in 2013. By 2012, Grandpa Qian had mid-stage dementia, and he was very restless and demanding. Even though Grandma Zuo had high blood pressure, heart disease, and frequent headaches, she was his primary caregiver, doing most of the caregiving tasks required to sustain him.

Taking care of Grandpa Qian was a big job. His schedule was erratic, and he was often very active around the clock, meaning that Grandma Zuo only got 3–4 hours of sleep per night and a one hour nap in the afternoon. Grandpa Qian demanded that his wife serve him warm meals up to six times a day, at all hours of the day and night, of which he often only took a few bites before getting up to wander. Also, he could not be left on his own, because, if hungry and left to his own devices, he would eat raw or rotten food and dirty things. Food had to be served at just the right temperature—not warm enough and he would be unhappy, too hot and he would burn himself, and either way he would yell and curse. When confined to the house, Grandpa Qian would lash out at Grandma Zuo, bang on the door and the walls and window, and throw everything from the shelves and drawers out onto the floor, breaking things. As a result, Grandpa Qian spent most of this time wandering the crowded neighborhood alleys. Sometimes Grandma Zuo walked with him, but other times in order to have food ready for him, get some housework done, or grab some sleep, she had to let him roam on his own. Also, Grandpa Qian became testy if he began to feel that his wife was following him. As he wandered the street, sometimes up to nine hours a day, he was looking for money that he thought he had lost. He wandered at all hours, urinating in doorways, taking neighbors' newspapers and laundry that was hung out to dry, and breaking outdoor flower pots and other items. At times, he picked fights with neighborhood boys. Many neighbors empathized with Grandma Zuo's situation and/or knew Grandpa Zuo to be a nice man before he got sick, and thus put up with his behavior without too much complaining. Others, with less patience or not knowing the family, reported him to the neighborhood residency committee. When things built up to a serious level, Grandma Zuo would get a home visit from the residency committee, asking her to please try to rein in her husband.

The elderly couple had 4 children and 3 grandchildren, all living nearby, but not one of them was able to help out much. Nonetheless, Grandma Zuo considered them all very filial, as their intentions were good. Despite the proximity of and getting some help from her children, even now in her ninth decade of life, Grandma Zuo still did a great deal of housework and most of the daily care for her husband. She stated that other than laundry, she did all of the other housecleaning chores, because her children were “too busy to help her with that.” To her, this was not a criticism or complaint, but a statement of fact. They were busy, and she was “still capable” (还能干).

One important obstacle to their adult children helping more had to do with a paranoia that Grandpa Qian had developed since he got sick. “He is afraid that our children, especially our son, are after his money,” explained Grandma Zuo. Grandpa

Qian would keep a large wad of cash in his pocket that he counted multiple times a day. He would not let any of his children over the threshold to their apartment as he thought that they were going to steal something. He also thought that his children were trying to poison him, so he would not knowingly eat any food that had come from his son or three daughters or from his daughter-in-law or sons-in-law. He was particularly leery of his son who he thought was the most likely to steal from or poison him, as sons are traditionally most likely to expect an inheritance. There was not much the children could do to help.

With regard to her children's genders and caregiving assistance, Grandma Zuo said: "Sons are the reputation of the family, but daughters are the lining (of a jacket)," (儿子是面子, 女儿是里子) meaning that daughters are more fundamental and closer to the heart and to practical needs. Her son did some to help, but not nearly as often and as much, and he was not the one who talked about matters of the heart with Grandma Zuo. Now that her husband was sick, it was her daughters and her younger sister to whom she turned for heart-to-heart conversation and emotional support. The elderly couple's daughters took on the role of rotating attempts at stealth deliveries of groceries and sneaking to do their parents' laundry. The son's only task was to take his father to the neighborhood public shower once every week or so to try to get him clean. It was a physical struggle to do so, as it meant getting off the pants with the wad of cash in the pocket and quickly replacing the wad into an identical but clean pair of pants. The rest was up to Grandma Zuo.

As to economic support and covering their expenses, Grandma Zuo was proud that she and Grandpa Qian had not had to rely on their children thus far for material support, and they had a nest egg tucked away in the bank in case of future health emergencies. Together through their combined pensions, Grandma Zuo and Grandpa Qian took in about 4000 yuan per month, a nice middle income for a family of two in Shanghai today, though you would not guess it from their Spartan housing conditions. In fact, these housing conditions were a reflection of the thrift of many Chinese elders in their generation. Living in run-down Mao-era work-unit issued subsidized government housing that was slated at some time in the future to be razed as it was considered too substandard for future generations, their rent was only 25 yuan a month, about the amount you would spend to purchase two large bowls of noodles with vegetables and little chunks of meat and spices from a lunch cart on the street. Their one-room apartment was about nine feet long and twelve feet wide with a dark narrow hallway for cooking in the back corner. Their bed, a table, two kitchen chairs, two stools, a refrigerator, a fan, a counter, and a television set all fit snugly into that one room. The room was neat and tidy, although being on concrete on a ground floor in the damp climate of Shanghai, there was a slight scent of moldiness in the air. Like many of their neighbors, Grandma Zuo and Grandpa Qian had no indoor plumbing or running water in their apartment. They got water from an outdoor neighborhood spigot, cooked on a small double burner coal gas stove in the back corner of their room, and used an enamel basin as a toilet which they dumped outside in a communal toilet. To save money, they did not have a telephone in their home and instead they used their daughter's phone next door when they needed to make or receive calls.

Grandma Zuo said that since this was the way that they had always lived, they were used to it, and none of these inconveniences bothered them. Since they lived frugally and had health insurance through their former jobs which paid for 85 % of their covered medical expenses, the couple spent only about 2000 yuan a month. The remaining 2000

yuan was deposited in their bank account each month as savings in case of a health emergency in the future. Even though they had health insurance, they still needed access to large amounts of cash, because in China hospitals will not save your life unless you give them a deposit, usually of at least 3000–5000 yuan up front. Much of what they did spend was on food and groceries, 200 yuan on electricity, water, and coal gas, and most of the rest was on medications and doctor visits, not for Grandpa Qian, but rather for Grandma Zuo. To treat the high blood pressure and heart disease that she had developed five or six years ago soon after beginning to take care of her sick husband, Grandma Zuo now had to spend 700 yuan a month for checkups and medications. Grandpa Qian used to take some medication for his dementia, but they no longer had that expense, because after becoming paranoid of being poisoned, he refused to take any medication. Since Grandma Zuo had heard that the dementia medication that he had initially taken can only slow down the disease a little bit and not stop it, she was not concerned that he had stopped taking it.

Adult day centers and nursing homes would not take Grandpa Qian. He was too disruptive and violent. As Grandma Zuo put it, “Nursing homes will not take patients like him who raise a ruckus (闹事的).” Furthermore, with his paranoia, he would not take any medicine to calm him, fearing that it was poison, and he would stubbornly refuse to go. Even if a nursing home would take him and they could get him to go, their combined pensions were not enough to cover the kind of money that it would cost for that kind of care, which they estimated would run at least 5000 yuan a month. Grandma Zuo also saw no reason to waste their hard-earned pension money on something that she could do herself. Furthermore, Grandpa Qian would be irate if he thought his money was being spent that way. When questioned about the idea of asking their children or grandchildren for some money to help cover nursing home expenses for the two of them if an option became available, she stated emphatically that they did not want to take money from the younger generations in their family: “The thought—asking my kids to pay money out of their own pockets for us to stay in a nursing home! Never! ... My son and daughters are all already retired! My son is all of sixty! My daughter-in-law, my daughters and sons-in-law, they have all retired (and are on limited incomes). We do not want money from them. We have our own, we two. We have enough for our needs. We do not need their money.” Asked about help from grandchildren, Grandma Zuo replied: “They have their careers to be vigilant about. Us two, we are of no use any more (to society) (没有什么用了),” signaling that the money was better spent on their grandchildren’s future. So, the only thing left was for Grandma Zuo to manage largely on her own and continue to take care of Grandpa Qian at home. When the residency committee or neighbors came to her to complain about his neighborhood misadventures, she would say, “Why don’t you think of a way to call the police and have them capture him and put him in jail?! I don’t have any way (to contain him)!”

When asked, Grandma Zuo said that they did not receive any public subsidy or goods or services for the elderly, and that they didn’t really need or want anything from the government along those lines. Anyway, she said, it was a moot point, because they did not qualify for assistance as they were not in the category of “old people living alone” (独居老人). With some annoyance, she said that she didn’t want any help from the residency committee, because all they did was come to chat and tell her to control Grandpa Qian but gave her no help in doing so. With follow-up questioning, it came out that Grandma Zuo did have one hour per month of government-subsidized housework assistance from an hourly worker. The hourly worker was one of several who

were hired by the local government to do some household chores for a large clientele of neighborhood elders in Shanghai over the age of eighty, with an allotted time of one hour a month per household. It is a function of how much of a token this program is generally perceived to be by most elderly people that Grandma Zuo did not remember to mention it. Although this relatively new program was entirely free to the seniors who used it, and they could ask the hourly worker to do any housework, they tended to see it more as a symbolic gesture of concern by the local government's residency committee than as real instrumental help with matters of necessity. The government-hired senior housework hourly workers in Shanghai were usually female migrant laborers from rural areas such as Anhui Province, and the elders usually had them do some chore that didn't need to get done and didn't require much skill, but which was a nice extra. Many seniors mentioned having the hourly worker wash the windows. Also, many elders did not trust the migrant workers who the government hired as they were considered too low quality to be trusted with important work and were often under suspicion for having sticky fingers, a function of the stigmatized position of rural migrant labor in China today. Washing windows kept the worker in full view of the elders and out of their stuff. Grandma Zuo used her hour to have the worker clean and fetch things from the loft area of their apartment (a two by six foot supported shelf in the back corner of the room) where they stored seasonal and less-often-used odds and ends and which was hard for her to reach as it required climbing a rickety little ladder. Community leaders shared with us that many elders did not usually work the hourly laborer very hard or even for the full hour, because they took it as a matter of pride that they were self-sufficient and well-off enough to be magnanimous to the help. It was also stressful to have to supervise help who they did not trust and who they were not themselves paying. In Grandma Zuo's case, if Grandpa Qian was around when the hourly worker came by, she had to be sent away, lest she raise his ire as an "intruder."

Grandma Zuo assigned many meanings to her caregiving for Grandpa Qian. Those meanings included: marital reciprocity, marital duty, the duty to not burden children, and fate or karma (命运,因果报应). With regard to marital reciprocity, marital duty, and duty to children, Grandma Zuo said:

Before if I got sick or something, he would very much concern himself about me (关心我) and how I was doing. Now he doesn't know. ... If he were not sick, then he could take care of me (他也会照顾我).

After so many years, more than sixty years, you don't have a choice (没有办法). The only thing you can do is to eat a little bitterness (吃苦) [that is, suck it up and do what you've got to do]. There is no alternative. ... We take care of our own (咱们照顾自己的). We do it ourselves (自己做). There is no other way (没办法的).

Taking care of him is something that I should do (我应该照顾的). If I don't take care of him, who will? Our children have their own families now, their own children (孩子都有自己的,自己有孩子的). They have their own burdens (有自己的负担了).

Beyond responsibility and reciprocity, Grandma Zuo saw fate and karma in her predicament. She expressed this several times, in a number of ways: "My fate (命) is

after all just such a bitter one (真苦). It can be no other way.” “I must have wronged him in a past life (我大概是在前世冤枉了他), so it is my burden to bear (所以这个因该是我承担的).” “It is something that I should do, a responsibility, a duty (责任, 义务). I owe him from a past life (是我从前世欠他).” “Yes, it is that my own fate is not good (就是自己的命不好). I console myself (安慰自己) (by telling myself this).” “In a past life, I incurred a debt to him (从前世负债他). This life, I am paying him back (这辈子在偿还). You can’t go complaining about it – it’s your own fate that is no good.” This was another big reason why Grandma Zuo had been intent on and content with doing most of the caregiving on her own. She felt that in order to repay her karmic debt for bad deeds that she had apparently done in a past life, she had to suffer through taking care of Grandpa Qian, who must have been the reincarnation of whoever she had harmed. If she complained or if other people took on too much of the burden, she would not be released from that karmic debt, and it would continue to haunt her longer in this life, and perhaps into the next life, a spin that is not foreseen in most scholarly discussions of “caregiving burden.”

In between our 2012 and 2013 visits, Grandpa Qian died. He fell down on one of his walks, banging his head on the pavement. Then the next day he fell down again, and slammed his head hard on the curb. The whole side of his head and face were purple. The family tried to get him to go to the hospital, but he hit them and refused to go. Because there was no way he could get anything but worse with time, they just let him be. For a couple days, he just slept and got up to go to the toilet. On the third day, he couldn’t get up any more. That day he died in his sleep there in his bed at home. When Jeanne visited Grandma Zuo and her daughters six months after his passing just before they were about to sit down to lunch together, Grandpa Qian’s ancestor portrait was smiling down from the wall beside the table. Grandma Zuo and her daughters smiled too as they told how they had taken care of Grandpa Qian in the manner in which he had wished. They also spoke with gratitude about how he had also taken care of them to the very end by going quickly and neatly, toileting himself all except for his very last day. “So, I have paid off my karmic debt (呐, 我解脱了),” Grandma Zuo said with a sigh. “She has paid her karmic debt” (解脱了), her daughters affirmed. We said a goodbye of mixed tears and smiles before they began eating a leisurely meal together.

## CODA

With time, change came to the situations of many of the couples who we had visited. Unfortunately, Grandpa Qian was not the only one to die. By 2014, more than ten of the original 30 care recipients and one of the original caregivers (Grandma Huan) had passed away. Over time, some of the participants in the qualitative arm of our study came to need additional help, necessitating a change in their living situations. By 2013, two couples had their daughter come to live with them, and by 2014, two more couples had moved to live with their adult children. In addition, at least one care recipient had moved into long-term hospital care outside the home. Other changes in living situation were associated with relocation in association with local gentrification projects. These cases were lost to follow-up, such that we are not sure whether they maintained situations of spousal primary care or whether care by adult children or institutional care became more dominant. Nonetheless, these changes in circumstance do not

diminish the fact that the older adults we visited had each spent numerous years to over a decade taking care of their spouse. These are accomplishments that should not be overlooked. Furthermore, it should also be noted that it was not just Grandma Zuo who noted the reciprocal care provided by care recipients either earlier in their lives and/or even as they become heavily reliant on others.

## Discussion

Both the quantitative survey and qualitative participant observation and interview results suggest that older adults play an important role in eldercare for aging in place in the Shanghai community that we examined. While the results of both of these methods of data collection pointed in the same direction, they each also gave distinctive insights into the social distribution of and the cultural meanings and social processes associated with familial and spousal eldercare for aging in place.

The survey results showed that spousal caregivers and other older adults such as neighbors, friends, and siblings had significant representation in identifying as primary caregivers. In addition, many of the adult children claiming this role were old or nearly old themselves. When taken separately, spouses were about as important as adult sons and adult daughters in the provision of care for aging in place. Interestingly, these results on spouses versus adult children were very similar to those of another small household survey of eldercare provision undertaken in Shanghai in 2013, again with spouses, sons, and daughters each making up 20-something percent of those identifying as primary caregivers (Yin and Zhou 2014).<sup>4</sup> Clearly, these survey results show that older adults and elders' spouses play an important role in supporting aging in place in Shanghai today. The young and middle-aged, adult children, and daughters-in-law do not represent the full variety of those identifying as providing significant amounts of eldercare.

Our broader ethnographic fieldwork shows that spouses may in fact play a larger role in at-home eldercare than what is suggested by survey results. While the survey results showed that, taken together, adult sons and daughters were more likely to be the primary caregivers of home-dwelling elderly, our years of participant observation and informal conversations in the community give us several reasons to believe that spousal care may be underestimated by such methods. First, local residency committee cadres and NGO affiliates with long years of experience in these neighborhoods stated that they felt that spouses did more eldercare in the community, but that this often went unrecognized. Second, in informal conversations with residents, we found that spouses often did not count their eldercare activities as “eldercare” per say. To spouses, caregiving was often seen as merely an extension of married life and a continuation of long-term spousal reciprocity. Some husbands or wives engaging in significant amounts of caregiving may not see themselves as *caregivers*, as the term caregiver tends to imply an exclusivity of roles—you give or receive care, not both. Since spousal relationships tend to engender a sense of give-and-take, the line between mutual spousal care and spousal primary care can be blurry. Third, during our own visits to

<sup>4</sup> In that 2013 Shanghai study of 311 home-dwelling elders with difficulties in performing activities of daily living (ADLs, e.g., feeding, toileting, bathing), it was found that a roughly equal number were cared for by spouses (27.3 %) and daughters (29.6 %), followed closely by adult sons (22.8 %) (Yin and Zhou 2014: 132).

family households, we found that sons and daughters had a much lower threshold for counting their supportive activities as eldercare than elders' spouses did. Sometimes an elderly spouse would be spending the same or a greater amount of time doing eldercare tasks, but only the adult children's efforts would receive attention. This is because children's filial eldercare has traditionally been culturally marked in Chinese discourse, whereas spousal caregiving has largely gone without saying. Fourth, the survey did not ask for a list of all caregivers involved in the elderly household members' care, only to talk with "the primary caregiver." Since in the lower middle income households in this area, adult children are generally thought to be more articulate than their parents due to rising educational attainment over the generations, they would often be more likely to be identified as the one to speak for the household. In that their efforts as adult children would be more culturally marked as eldercare and more apparent to them in a subjective sense, this may have led to inflation of the number of adult-child "primary" caregivers captured by the survey.

Yet, despite its limitations, our survey data is helpful for showing the relative distribution of various self-reported traits within the target population. Nonetheless, future surveys should do more to attend to the tricky question of the correspondence between self-identification and social identification as caregiver or primary caregiver and the objective amount of assistance someone is actually providing to the elder at hand. In addition, they should do more to recognize that there may be multiple primary caregivers whose assistance is critical to sustaining the life and wellbeing of the care recipient. With such modifications, we believe that future surveys are likely to register an even greater contribution to familial eldercare on the part of older adults and elders' spouses.

Even more so than our survey results, our interview and participant observation findings show that older Chinese adults are making important contributions to in-home eldercare in contemporary Shanghai. These qualitative results go further than our survey findings to describe some of the reasons why seniors choose not to rely on their children for eldercare. Such reasons include elders' not needing to do so due to pensions and health benefits, pride in their independence, not wanting to deplete their children's time or resources, and/or wanting to fulfill ideals of marital reciprocity or pay off karmic debt. They also show how being a spousal "primary" caregiver does not preclude some senior self-care, spousal mutual aid, change in relative spousal roles over time, or the perception of a certain degree of past or continued spousal reciprocity. Such qualitative findings show the limitations of surveys which insist on one main primary caregiver and/or freeze roles into givers and recipients of care at one limited point in time. Our ethnographic findings also show that primary reliance on spousal or familial care does not preclude the need for supplemental assistance from community-based services to make such aging in place sustainable over time. They also show that there are important gaps in formal respite services and institutional options for seniors who have disruptive behavior.

While quantitative methods leave one wanting for subjective meanings, social context, and interpersonal dynamics, like all qualitative studies, this one is limited in terms of not being able to tell us exactly how widespread these social patterns or cultural meanings are in the wider population of older adults in Shanghai. In order to get a better handle on both distribution and sociocultural context, we will need many more mixed methods studies on this topic, especially ones with a tighter alignment in

instrumentation and sample populations between the quantitative and qualitative arms of the study. In both cases, special attention should be paid to the notion of a “primary caregiver” and how to best operationalize attendant questions about self-identification, social identification, and objective measures of various dimensions of caregiving tasks. Gaugler et al. (2002) have raised the issue of wide variation in terms of scholars’ definitions as to what counts as family caregiving or familial primary caregiving. Future studies should take care to make such definitions and their operationalization clear so that study results can be appropriately interpreted. The dominance of biomedical definitions focused on ADLs should not preclude the inclusion of other facets of care, including affirming the care recipients’ value, being present with them, listening to them, making sense together of what is going on, providing emotional support (Kleinman 2010), or assisting with seeing or hearing things. In addition, attention should be paid to issues of spousal reciprocity within and across time frames and the possibility of simultaneously or consecutively being both caregiver and care recipient.

## Conclusion

Although China’s recent national aging policies do make brief mention of eldercare by the aged, they do not do enough to recognize its importance, with the effect of all too often painting an overall portrait of seniors as a needy burden. While it must be conceded that these policies were primarily designed to protect elders from neglect and abuse, rather than catalogue their contributions, we would argue that the degree of public focus placed on these policies has contributed to keeping public discussions of eldercare centered on the tired old notions of elder dependency, caregiving burden, and Confucian filial piety. In so doing, dominant public representations of elders have missed a great deal of what is going on in the aging of contemporary Chinese society, as evidenced in the above survey results and qualitative findings on eldercare by seniors within the family in Shanghai.

These findings suggest that scholarly and policy arenas should pay as much attention to older adults’ continuing contributions to family and community as they do to their needs if a more accurate picture of China’s aging society and the development of sustainable social programs are to be realized. We think that this research suggests several critical gaps that need to be addressed with regard to eldercare policy, research and services in China. As other researchers have pointed out, the role of seniors in eldercare may be even more important in rural areas of China which are marked by the exodus of youth and will be increasingly important as China’s national population soars toward 30 % elderly by 2050.

First, we need more policy recognition of the caregiving contributions of older adults in China, and these contributions need to be better publicized in policy briefings and press releases. While care should be taken not to swing the pendulum too far leaving seniors to fend for themselves, a better balance in rhetoric and planning must be struck between seniors as people with needs and interests and elders as responsible contributors to society. Of course, while distinctively contoured in each location, this is a problem that many societies share, including developed western nations.

Second, we need further research and better scholarly documentation on informal elder care by both related and non-related older adults in China, with a particular focus on spousal caregiving, in order to form a foundation for policy. This research should be



conducted in a much wider variety of rural and urban locales, socioeconomic statuses, and family situations in order to get a better handle on the parameters across diverse circumstances. We also need wider coverage in terms of both qualitative and quantitative studies to gauge both the prevalence of various scenarios and the social meanings and processual characteristics of those situations. Local cultural and generational notions of support, contribution, care, caregiver, primary caregiver, independence, dependence, and interdependence will vary, such that enumeration by survey must be complemented with a meaning-centered, multi-perspective view of everyday life in community context over the course of time.

Third, in terms of services, more attention needs to be paid to the personhood of seniors and what different population niches feel that they most need. We need to actively involve more seniors in helping to set eldercare program priorities and contributing to service delivery design and assessment. The power of senior mutual aid, cooperative enterprises, and volunteer capacity should be more systematically utilized and publicly recognized. We should carefully consider whether certain services such as centrally-administered home housekeeping services are cost-effective and should be a priority for funding. In our fieldwork, we found that many seniors would rather be given a stipend to hire their own home help so that they can screen them in person for trustworthiness and have the power to hire and fire. More public funding and program support is needed for seniors providing eldercare in their homes who are not over eighty years old and who have children but not necessarily children who can be of much help. Finally, there is a desperate need for full-time residential, day programs, and respite alternatives designed for elders with dementia who act out.

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### **Compliance with Ethical Standards**

**Ethical Treatment of Experimental Subjects (Animal and Human)** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This research was approved by the Institutional Review Board of the University of Vermont and Case Western Reserve University.

**Informed Consent** Informed consent was obtained from all individual participants included in the study. All names of research participants used in this article are pseudonyms.

**Conflict of Interest** The authors declare that there is no conflict of interest.

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