



Kent Academic Repository

Zhang, Jinbao, Wang, Julia Shu-Huah, Chan, Wing Kit, Chen, Yongen and Lan, Danhong (2024) *Conundrums in Implementing Consumer Direction in Home-Based Care: Perspectives of Older Adults and Family Members in China*. *Journal of Aging & Social Policy*, 38 (3). pp. 414-434. ISSN 0895-9420.

Downloaded from

<https://kar.kent.ac.uk/107893/> The University of Kent's Academic Repository KAR

The version of record is available from

<https://doi.org/10.1080/08959420.2024.2422665>

This document version

Author's Accepted Manuscript

DOI for this version

<https://doi.org/10.22024/UniKent/01.02.107893.3445136>

Licence for this version

CC BY (Attribution)

Additional information

For the purpose of open access, the author has applied a CC BY public copyright licence to any Author Accepted Manuscript version arising from this submission.

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in **Title of Journal**, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

Conundrums in Implementing Consumer Direction in Home-Based Care: Perspectives of Older Adults and Family Members in China

ABSTRACT

Consumer-directed care (CDC) for older people enables clients to arrange personalized services and improves their well-being. However, little is known about clients' preferences for policies in collectivist cultures. We investigate the views of older clients and family members about policies that promote consumer direction in a collectivist cultural setting—Guangzhou, China. Using semi-structured interviews, we recruited older persons and their family members (n = 24) in 2021. Inductive thematic analysis was employed. Two themes emerged. The first theme, the need for flexibility in utilizing benefits, includes the need for: 1) flexibility in selecting care workers; 2) autonomy in choosing budget management agents; 3) flexibility in selecting care-related goods; and 4) adequate and equitable benefits. The second theme, the need for professional support, contains the need for: 1) information and support; and 2) individualized training for care workers. Similar to those in individualistic cultures, people in collectivist environments desire autonomy and choice in service arrangements. However, the welfare and preferences of family members, rather than clients, may be prioritized by family members when making care decisions. Adapting CDC to collectivist cultures requires navigating between client preferences and family preferences.

Keywords: self-direction, cash-for-care, participant-directed care, long-term care insurance

Key Points

- Because CDC was developed in individualistic cultures, little is known about how it might work in collectivist cultures.
- People in collectivist cultures desire consumer direction in service arrangements.
- CDC implementation in collectivist cultures prioritizes family preferences over client preferences.

- Policymakers could improve benefit flexibilities and offer professional support to develop policies.

Introduction

Consumer-directed care (CDC) permits older adults to flexibly arrange home-based services for themselves. This service model stands in contrast to the conventional agency care (CAC) approach, characterized by a top-down, professionally dominated system that imposes standardized care arrangements on individuals (Christensen & Pilling, 2014). By transferring decision-making power to clients, CDC enables older adults to exercise autonomy in determining the types of services needed, scheduling service delivery, and selecting care providers.

CDC are designed differently across countries with some common elements. A comparative policy analysis of 11 CDC programs across seven countries, including Germany, Spain, the United Kingdom, and China, revealed two commonly implemented policy designs: allowing clients to transition freely between CDC and CAC, and offering counseling to inform consumers about their rights, responsibilities, and available resources (Zhang et al., 2023). In addition, many CDC programs offer support in managing CDC budgets and grant the flexibility to choose care workers (Kan & Chui, 2021; McCaffrey et al., 2015; Moran et al., 2012). These features highlight the need for choice, information, and support among clients and family members, which are key factors in the effective implementation of CDC programs across countries.

Despite these similarities in CDC design directions, cultures may influence policy practices and individual preferences regarding CDC. In individualistic cultures, such as the United Kingdom, CDC is used to empower older people to organize their services rather than protect informal caregivers (Da Roit & Le Bihan, 2019). In contrast, the goal of CDC in some countries (e.g., France and Austria) is to support families and compensate family caregivers in absence of in-kind services, with less emphasis on choice and control (Da Roit & Le Bihan, 2019). Additionally, people with different cultural values may have distinct preferences and

expectations regarding CDC policies. For instance, compared to White consumers, African American and Hispanic consumers were found to be more interested in using CDC cash options since their cultures emphasize family networks, mutual care, and bringing more caregiving jobs to their communities (Mahoney et al., 2004; Sciegaj et al., 2004). Though previous studies have demonstrated that individualistic and collectivist societies have distinct care practices (Wada, 2015), the extent to which CDC programs cater to these different cultural preferences is absent from the current literature.

The purpose of this research is to investigate older persons' and family members' preferences for policies that facilitate consumer direction in a collectivist cultural setting: Guangzhou, China, which has recently introduced CDC alongside CAC options. This study contributes to the understanding of consumer preferences for CDC implementation practices in a context where family values dominate care practices. The findings can inform policymakers on how to effectively balance personal preferences and family needs in CDC programs, thus optimizing services for older persons.

Culture, Care Practice, and CDC

Culture refers to a set of beliefs, values, and customs that shape individual and group behaviors, as well as care practices. Cultures can influence care practices, policy directions, and the focus of CDC research. First, with respect to care practices, cultural factors influence whether and how some older clients' autonomy and independence are valued. People in individualistic cultures typically express themselves as distinct physical entities and value independence and personal autonomy (Fung, 2013). Influenced by these norms, family members and care professionals tend to encourage, support, and optimize clients' preferences and interests when making care-related decisions (Hengelaar et al., 2018).

In contrast, collectivist cultures emphasize interdependence, relational harmony, and prioritizing the needs of the community over individuals (Fung, 2013). Although East Asia

and Southern Europe share similar collectivist values, the two regions differ in their attitudes toward personal autonomy. In East Asia, the needs of family and society often override those of individuals, and decision-making typically involves seeking consensus (Choi, 2007). When conflicts arise, many adult children adhere to Confucian hierarchical principles and obey older parents' decisions. However, a shift toward prioritizing the welfare of adult children can occur when parents experience a decline in functional capacities and when the influence of Confucian values is waning (Abrahamson, 2018; Ziliotti, 2022). Thus, the personal autonomy of older parents has traditionally been highly valued, but this is changing as Confucian values diminish or when older adults experience functional declines. Despite Southern Europe being characterized by strong family ties, individual autonomy is honored because Catholicism usually emphasizes the dignity of individuals (Ferrero et al., 2016; Mönkediek & Bras, 2014). Overall, autonomy and independence are generally not as valued in East Asia as they are in individualistic cultures and Southern Europe (Nakagawa et al., 2018). In East Asia, care-related decisions tend to favor family welfare over clients' own autonomy and preferences because older clients often prefer avoiding family conflicts and achieving relational harmony (Chen, 2017; Wada, 2015).

Second, CDC policy discourse varies among different sociocultural systems. In Australia, England, and the United States (US), CDC is a lever for transforming the power dynamic in care relationships to achieve equality between professionals and clients (Da Roit & Le Bihan, 2019; Wada, 2015). In Southern Europe (e.g., Spain and Italy), CDC typically grants cash benefits to family caregivers and is an instrument to compensate and reinforce family caregiving in line with the cultural value of moral responsibility (Da Roit & Le Bihan, 2010; Da Roit & Le Bihan, 2019).

East Asia and Southern Europe differ in policy focus. In East Asia, Confucian cultural principles have influenced the evolution of welfare systems, labeled as Oikonomic welfare by

Jones (1990), prioritizing citizens' responsibilities over their entitlements (Goodman & Peng, 1996; Jones, 1990). Confucian values deeply permeate welfare structures, encompassing filial piety, paternal benevolence, prioritizing the collective over the individual, avoidance of conflict, and adherence to duty (Abdul Karim et al., 2010; Goodman & Peng, 1996). Increasingly, the state in East Asia has played an important role in providing care (Abrahamson, 2018). Long-term care policies, like Hong Kong's community voucher scheme and Japan's long-term care insurance (LTCI), aim to alleviate the strain of family caregiving by enhancing formal care services and spreading care responsibilities across society. Unlike policies in Southern Europe that provide financial compensation for family care, various policies in East Asia emphasize the socialization of care (Campbell et al., 2010; Wada, 2015). Accordingly, CDC programs in East Asia typically subsidize clients to choose among non-family care providers (Kan & Chui, 2021). One exception is the LTCI experiment in Guangzhou, China, where the system enables older adults to select between family and non-family care providers consistent with their wishes and cultural norms.

Third, prior studies have consistently suggested that CDC improves individuals' health and quality of life across various cultural contexts, despite variations in CDC policies (Ottmann et al., 2013; Wada, 2015). Accordingly, the research focus has shifted from demonstrating CDC's effectiveness to understanding how best to improve and implement CDC programs, especially in Australia, England, and the US (Steiner et al., 2022).

In sum, existing studies have suggested that cultural systems can affect care practices, policy directions, and CDC research focus. CDC programs evolved out of and are informed by Western culture's emphasis on individualistic values (Ottmann et al., 2013). However, little is known about whether the complex interactions of family relationships in East Asia are compatible with CDC programs' emphasis on individual preferences. Additionally, users' views are vital for informing policymakers in tailoring services to users' expectations and

cultural values, an aspect that has been less explored in collectivist cultures. This study explores older clients' and family members' experiences and expectations regarding consumer direction in a collectivist society.

LTCI in Guangzhou

As one of China's largest metropolises, Guangzhou is the administrative and cultural center of Guangdong province. In 2020, the share of people aged 65 or above in Guangzhou was 13.01%, close to the figure for the whole nation (13.50%). To address the ever-growing care needs of its older citizens, the Guangzhou government launched LTCI in August 2017 (more details about LTCI in China can be seen in Appendix A). Prior to that, the government provided no publicly financed formal care for residents, except subsidies for low-income families. Under the LTCI program, people with functional impairments are entitled to receive benefits. Recipients can choose between home-based services and institutional care, but individuals incur higher out-of-pocket expenditures for institutional care due to its increased costs. Home-based clients can receive personal and medical care and rent care-related goods specified by the government, such as wheelchairs and rehabilitation devices. Notably, clients must choose goods from a restricted set of suppliers licensed by the government.

Guangzhou's LTCI features generous coverage and flexible benefit utilization. Unlike many other pilot cities exclusively insuring urban employees who are physically impaired, Guangzhou has expanded the benefit coverage to urban or rural residents and those with intellectual disabilities since January 2022. Additionally, the government permits home-based clients to hire care workers, including family members, rather than use care agencies that are typically required in most pilot cities, such as Shanghai and Qingdao.

Although LTCI is a newly established program and older people have limited knowledge of the services, the government has not established information channels or designated information providers, such as residents' committees (*Juwei*, the lowest

administrative level which are typically responsible for facilitating social services delivery and government-resident communication in urban China) and home care agencies (Zhang et al., 2023). The lack of such information channels hinders people in using LTCI. As a result, private for-profit agencies commissioned to provide home-based services are motivated to promote LTCI as they can charge fees to clients. Appendix B (Figure B1) illustrates application procedures and the process by which eligibility is determined for home-based services.

LTCI grants flat-rate benefits, regardless of clients' income or assets and the availability of family caregivers. Urban (former) employees with a work history in formal sectors receive, on average, higher benefit amounts than urban residents without a formal work history and rural residents regardless of work history. Appendix C (Table C1) shows the level of benefits among urban employees and rural and urban residents. These disparities reflect China's occupation-based welfare provision system, where public spending favors urban employees since they and their employers have contributed to social insurance systems. In Guangzhou, the LTCI benefit level is 50% higher for former employees than for urban or rural residents. Additionally, the budget cannot cover all care-related costs, and individual and families bear the costs of services exceeding the subsidy.

Guangzhou's home-based services grant clients options between agency-directed and self-directed care workers, and these service approaches align with the definitions of CAC and CDC, respectively. CDC empowers clients to express care preferences and control their care arrangements, such as hiring and dismissing care workers. In contrast, under the CAC service model, care agencies employ and fire care workers, schedule and manage services, and are responsible for paying care workers, with clients having no formal control over their service arrangements. Under CDC, family members and domestic helpers can be employed as care workers, and they must complete standardized training courses in caring for older

people. Though policies do not impose any constraints on the choice of care workers, in practice, care agencies have autonomy in promulgating guidelines that require CDC recipients to employ care workers under 65 years old to ensure the physical competence of self-directed workers.

While policies serve as the scaffolding for implementing LTCI and empowering clients, research pertaining to LTCI in Guangzhou is limited, and policy preferences among consumers in this region remain unknown. To address these gaps in knowledge, we explore older clients' and family members' preferences for policies that enhance consumer direction in Guangzhou. We have four initial hypotheses: (1) Older people and family members desire choices to meet their preferences. (2) Family members' interests may override older clients' preferences and welfare. (3) People using CAC may wish to exercise consumer direction but encounter barriers. (4) Compared to urban employees, urban or rural residents are forced to choose CDC and hire low-paid family members due to inadequate benefit levels. To our knowledge, this study is the first to explore consumer preferences in the LTCI system in Guangzhou, a context of collectivist culture and paternalism where the government is expected to provide welfare services and the residents are passive recipients with limited choices and autonomy (Ma, 2021).

Methods

Study Design

We conducted semi-structured interviews with 24 individuals — 6 LTCI clients (age 60+) and 18 family members of LTCI clients — in Guangzhou between April and August 2021. Participants were purposively sampled, and data were interpreted using inductive thematic analysis.

Participants

We recruited older clients and family members with the help of two agencies with rich experience in serving people with functional limitations in Guangzhou. Both were private for-profit companies that provided information about LTCI and delivered care for self- and public-funded clients. Nurses from the two agencies contacted individuals and determined their interest in participating in the present study. Inclusion criteria included (a) clients aged 60 or above or their family members and (b) those who were cognitively intact and able to speak and understand Cantonese or Mandarin. In this study, we used the term “participants” to represent both older clients and family members when their preferences aligned. When differences emerged, we explicitly described them.

Purposive maximum variation sampling was adopted to obtain a spread of characteristics across participants. We were interested in capturing and depicting shared experiences among this heterogenous group of people. Accordingly, we ensured the inclusion of (a) clients and family members, (b) individuals using either CAC or CDC services, and (c) persons receiving different benefit levels (i.e., urban employees and urban or rural residents). These groups of participants may have different preferences and experiences regarding consumer direction. By analyzing these experiences, we aimed to identify common themes across various groups.

Twenty-four individuals participated in the present study, including six older clients and 18 family members. Among these participants, one dyad of an older client and a family caregiver was interviewed. Participant characteristics are presented in Table 1. Male and female participants were evenly represented. Half of the clients were 85 years or older, and most family members were below 60 years old. Approximately two-thirds of clients received the benefit for urban employees, while nearly one-third received the benefit for urban or rural

residents. In all, 70.83% of clients and family members used CDC services, while 29.17% were CAC users.

[Insert Table 1]

Procedures

Interviews were in-person and conducted in participants' homes. Two researchers performed the interview in a quiet place with clients or family members. All clients requested the presence of their family members to sign the consent form and provide help (paraphrasing interview questions and ensuring that older clients could hear by speaking loudly when needed) during interviews, while family members were interviewed individually. Researchers had no prior relations with participants and provided no financial incentives for participation. An interview guide developed by the research team allowed the participants to share their experiences on similar topics (interview guide can be found in Appendix D). Example questions were "Who is the care decision-maker? How do you feel about that?" and "What would your life be like if you were the budget holder?" All interviews were digitally recorded and transcribed verbatim. The interviews lasted between 14 and 77 minutes, with an average length of 35 minutes.

Analysis

We used Braun and Clarke's (2006) approach to conduct inductive thematic analysis to analyze the data. This coding process relies on the data themselves instead of an existing coding frame. The analysis focused on the lived experiences of the participants and their perspectives on using home-based services and exercising consumer direction. Given the scarcity of existing evidence on users' views of CDC programs in China, we relied on the flexibility of inductive thematic analysis to explore individuals' motivations, feelings, and perspectives regarding consumer direction (Braun & Clarke, 2006). This approach was chosen because it facilitates coding and identifying themes and uncovering nuanced insights from the data without being

influenced by pre-existing frameworks. Reflexibility was incorporated throughout our research process to ensure that our interpretations remained authentic to the participants' experiences. Further elaboration on the analysis is available in Appendix E.

Results

Analysis revealed two primary themes and six subthemes. For the first theme, the need for flexibility in utilizing benefits (benefit utilization hereafter), four subthemes emerged from the interviews: a desire for flexibility in selecting care workers, the need for autonomy in choosing budget management agents, a desire for flexibility in selecting care-related goods, and the need for adequate and equitable benefits. The second theme, the need for professional support, emphasized assistance in utilizing benefits and managing services. We identified two subthemes: the need for information and support, and the need for individualized training for care workers.

Theme 1.1: Benefit Utilization: Desire for Flexibility in Selecting Care Workers

Flexibility in selecting care workers is essential for participants to improve service quality and psychological well-being. Although the CDC program targets older people who have the capacity to execute consumer direction, family members typically are the decision-makers, and their interests are often prioritized over clients' preferences.

Theme 1.1.1: Choice enhances service quality and a sense of hope

Flexibility in selecting care workers was important to exercise consumer direction. Participants described the freedom to choose care workers as an avenue to improve the quality of care and maintain a sense of hope. One participant perceived autonomy in choosing care workers as a means of "receiving better service because I can compare care workers from multiple sources" (Case 16, female, age 67, daughter, CDC). Another participant described feeling "calm and hopeful when I have so many choices of care workers. I'll use alternative

care workers and won't feel confused and uneasy when my family cannot help my husband. Choices are (emotional) anchors for me" (Case 19, female, age 72, spouse, CDC).

Theme 1.1.2: Choice for whom: Recipient's or the family members' interests?

Though home-based services target older adults and are designed to satisfy their needs, in practice, family members are often the parties exercising consumer direction by being the decision-makers and prioritizing their interests. Older adults remarked that family members were "reliable and trustworthy," while family members described older relatives as "being muddled" and "having no cognitive capacities" to make decisions for themselves, even when they were not cognitively impaired and could express preferences to researchers. Therefore, both older clients and family members indicated that family members acted as the decision-makers of the older adults.

Against this backdrop, clients' preferences and interests were not always honored in the decision-making process due to the welfare of family members being prioritized over that of the client. One client described how his preferences for family caregiving (CDC) were not prioritized even when his son was available to provide services.

The agency care worker comes and helps me. I feel embarrassed when she [the care worker] scrubs my body. My son is unemployed and living with me, and I wish him to care for me. But he doesn't. He hopes he would work and earn money to raise my two grandchildren. (Case 2, male, age 67, CAC)

In addition, many family members emphasized their own welfare during the care selection process. For instance, one client's daughter felt guilty about prioritizing her interests above those of her parents, compromising service quality:

My parents wished me to care for them because I could provide better services. The domestic helper gave them drugs, but they did not take them. They only trust me and take the drugs when I come or they hear my voice... But I have my family and need to care for my

grandson. I feel sorry for them. I cannot always prioritize my parents' preferences. (Case 9, female, age 60, CDC)

Theme 1.2: Benefit Utilization: The Need for Autonomy in Choosing Budget

Management Agents

Participants expressed diverse preferences for managing caregiving budgets and associated duties. Some participants wished to select agencies to administer the budgets. A 57-year-old family member wanted to manage the budget by herself to avoid financial exploitation. She said, "I'm afraid that the agency makes a profit from my budget [*Chishui*: improperly profiting by deducting from the budget]. The agency uses my money to pay rent and overhead costs."

Other participants did not want to assume administrative duties, preferring that the budget be managed by authority-commissioned agencies. A 50-year-old daughter stated, "I trust the agency and its care workers ... I feel depleted if I need to spend time managing the budget. It's suitable for me to let the agency manage my budget."

Theme 1.3: Benefit Utilization: A Desire for Flexibility in Selecting Care-related Goods

Participants reported limited autonomy in selecting care-related goods covered by the LTCI program. They noted that the government's catalog had limited choices, and many had already purchased many of the necessary items in the catalog. Consequently, clients' needs remained unmet, while the budget was inefficiently spent. One participant stated:

We bought the goods that can be covered by the government, such as a wheelchair and cane. We already have many canes and don't want to pick them up from the government. It's a waste of public resources... I wish the government allowed us to use the budget to buy health insurance for my mom. (Case 16, female, age 67, daughter, CDC)

In addition to wanting more autonomy in purchasing care-related goods or services, some participants also desired more items not covered by current programs, such as balm, incontinence briefs, and home modifications.

Moreover, the inflexibility in choosing goods suppliers inconvenienced clients and family members. One participant mentioned that she had to pick up goods from authority-commissioned suppliers far from her home:

I have to accompany my husband [the client] and go to the site specified by the government to pick up wheels [the wheelchair]. When we take subways to the site, I feel uncomfortable. People stare at us because of my husband's disability. (Case 15, female, age 57, spouse, CDC)

Theme 1.4: Benefit Utilization: The Need for Adequate and Equitable Benefits

Inadequate benefit levels impeded participants from implementing their care preferences, including hiring care workers and purchasing care-related goods. Although some participants expressed a preference for hiring non-family care workers, it is often unaffordable due to insufficient public payment amounts. Consequently, these participants resort to employing family members, who receive only meager subsidies from the government. One participant framed family caregiving as a forced option:

As the care worker, I feel stressed and tired. In the morning, I need to go grocery shopping. Then, I come back home in a hurry and make breakfast for my husband. After breakfast, I help him take medicine, check whether he has wet the bed, and bathe him. Next, I make lunch and give medicines to him. I repeat these things all day. This is a real headache. If I had a bigger budget, I would let the agency worker care for my husband. However, I cannot afford the wage for a formal care worker. (Case 18, female, age 72, spouse, CDC)

Additionally, some participants explained that they did not use care-related goods because the budget could not cover the cost. One participant said, “The benefit is low. How can I use it to buy equipment for my father?” (Case 8, female, age 52, daughter, CDC).

Given their lower benefits, urban or rural residents perceived inequity compared to urban employees who had a higher budget. Instead of feeling empowered, they perceived home-based services as a means of consolidating and widening the welfare gap between urban employees and urban or rural residents such as themselves. For instance, one participant described her distress compared with urban employees this way:

I appealed for more benefits but failed because my parents are urban residents and have a lower status than urban employees. In the eyes of the government, my parents are “the children of a mistress.” They have a monthly benefit of USD 98 (RMB 700), while the figure for urban employees is USD 280 (RMB 2,000). I feel stressed. (Case 9, female, age 60, daughter, CDC)

Overall, insufficient budgets often circumscribed consumer direction in selecting care workers and consuming care-related goods. Urban or rural residents compared their benefit amounts with urban employees, which caused feelings of inequity rather than empowerment.

Theme 2.1: Professional Support: The Need for Information and Support

Theme 2.1.1: Information about programs

Most participants believed that information about the recently initiated home-based services was lacking. Some participants described hearing about the program “by chance.” One participant said, “One day, my parents were sitting downstairs. The nurse happened to see us and reminded me that I could apply for the service. Without this chance occasion, I wouldn’t have known about it” (Case 9, female, age 60, daughter, CDC). Upon first hearing about LTCI, participants understood it as commercial products and often perceived it as a trap for paying premiums, fearing it might lead to financial exploitation, rather than viewing it as

a means for welfare provision. One participant described how she mistakenly regarded information providers as insurance agents:

There were many people selling insurance. Every time they called me, they asked me to buy insurance... One day, information providers from the insurance company gave me a paper flyer but said nothing. They asked me to go to their company... I didn't know them. How could I trust them and follow their words? (Case 14, female, age 57, spouse, CDC)

Surprisingly, even though they used the program, some clients did not know enough about it, including when they could start to receive LTCI benefits, the details of services, the budget amounts, and whether they contracted with care workers. Most clients knew nothing because family members had often helped them apply for the program.

Family members expressed the need for information about home-based services as they were actively involved in making decisions for the clients. Family members desired information from multiple credible sources, including the residents' committee, authority-commissioned agencies, and social and formal media channels (TV and broadcast). For instance, one participant stated that the residents' committee was suitable to provide information: "The committee should offer information because they are the government. They are reliable. If private companies provide information, it's not trustworthy. I worry about risks and deception" (Case 7, male, age 85, spouse, CAC).

Theme 2.1.2: Support with paperwork and managing payroll

When completing the required paperwork and handling the payroll of care workers, most participants received some assistance from family members and authority-commissioned agencies. Without this assistance, they felt overburdened rather than empowered. Support was most needed by those who chose CDC services, especially when additional paperwork was required for hiring self-directed workers. One client's wife, who

hired their daughter-in-law as the care worker, described the burdensome paperwork in the application process:

I wondered whether it was too complicated to apply for the program. There was so much paperwork I needed to complete that I almost chose to give up [the application]. When your family has a person who is bedridden or suffers from pain, how can you have enough time to consider other things? You feel upset and lose patience. (Case 19, age 72, CDC)

Furthermore, many participants reported anxiety about managing the payroll of care workers, especially those using self-directed care workers. One participant described the complex process of paying her domestic helper:

The agency is the proxy of the government to allocate budgets. The agency sends me a message and asks me to transfer my money (co-payment) to their bank account on the 10th of every month. Then, they return a part of my self-paid money, which is the government's benefits, to my account. I feel overburdened. (Case 16, female, age 67, daughter, CDC)

In summary, participants reported the need for support in managing paperwork and payroll duties so that they could better utilize home-based services, especially those receiving CDC. In contrast, CAC clients were less likely to assume these responsibilities because the agency often helped them.

Theme 2.2: Professional Support: The Need for Individualized Training for Care Workers

Training for care workers was seen as crucial for older adults to control service quality. Family members emphasized the role of training in enhancing the quality of care. For example, one client's wife who cared for her husband explained, "It's helpful. I didn't know how to give medicine or help him sit up because he couldn't straighten his legs in the past. After the training, I know how to help him. You should arrange which foot goes first when he gets off the lift" (Case 14, age 57, CDC). This narrative illustrates that training programs empowered

care workers to grasp caregiving skills, which eventually empowered clients and family members to control service quality.

Additionally, participants expressed the need for individualized training, such as administering spiritual comfort and first aid. Participants stressed that older adults had individualized needs but that the standardized training program did not improve skills needed to care for older people. One participant described the advantage of individualized training:

My father suffers from indigestion. Previously, we fed him with porridge and cabbage. The agency nurse saw our individualized needs and taught us lots of skills. For example, use Arirang (Dongbei) rice rather than foxtail millet to make porridge, and then, add sweet potato and some vegetables. Finally, smash the food to feed him. Now, my father is getting better and poos more regularly. (Case 17, male, age 53, son, CDC)

Discussion

This study examined policies that are necessary to promote consumer direction from the perspective of older people and their family members in China. The in-depth interviews revealed important themes. The first theme, the need for flexibility in benefit utilization, encompasses offering choices for selecting care workers, budget managers, and care-related goods, and providing adequate and equitable budgets to ensure that older people can access multiple service options and facilitate consumer direction. The second theme, the need for professional support, emphasizes that providing information and support and individualized training for care workers is essential to help older people implement their wishes and receive quality care. These findings highlight two conclusions, which we discuss in the following two paragraphs. First, older people's and family members' needs for choices and control over services in a collectivist cultural setting are similar to those in an individualist context. Consumer direction is desired by clients, regardless of their cultural background. Second, in collectivist settings, we found that prioritizing family members' welfare over older clients'

preferences can be a barrier to implementing consumer direction. Our findings underscore important areas for governments to improve CDC policies and implementation to enhance consumer direction.

We found that people in a collectivist culture often value choice, especially when selecting care workers, as is common in other CDC programs. In delivering welfare services, China is characterized by paternalism, where people, influenced by Confucian values and socialist ideology, are expected to have little interest in autonomy or control but seek support and care from governments and professionals (Ma, 2021). Interestingly, our work revealed that older adults and their caregivers preferred and pursued self-direction to fulfill instrumental goals, such as improving service quality and optimizing family welfare. This indicated that, as in individualistic cultures, CDC recipients and their caregivers share a preference for autonomy and choice. They desire that the Chinese government permits further individual control over service arrangements (e.g., choice of budget managers and care-related goods), which ultimately promotes service responsiveness and meets individualized needs.

Our findings also suggest that family direction, as opposed to individual direction, may dominate the care decisions and arrangements in the collectivist cultural context of Guangzhou. This does not necessarily imply that clients' and family members' preferences are often incompatible. Consumer direction and family direction can overlap. However, in a collectivist society, when the family and individual preferences are incongruent, practicing consumer direction and honoring preferences of older adults can be complicated and difficult. Typically, older people wish to maintain family harmony and rarely explicitly discuss their care preferences with family members. Family members, especially young adult children, exercise primary decision-making authority, including choosing not to provide care despite older clients' preferences for familial support. This misalignment contradicts Confucian

values, which dictate that adult children should dutifully obey and honor their parents' willingness. To successfully implement CDC programs and facilitate consumer direction at the policy implementation level, professionals (i.e., agency nurses in Guangzhou) could serve as important agents to ensure that older persons' preferences are incorporated when making care decisions. This could be done by encouraging older persons to express views and explicitly discuss their preferences with family members (Kramer et al., 2006). Hence, older persons' interests can be maximized when their voices are heard and considered by family members. At the policy design level, institutionalizing a formal family group conferencing approach, which ensures that views of various parties are solicited and deliberated in long-term care services, may also be a potentially viable approach (Parkinson et al., 2018).

In this study, we found that participants had diverse preferences for managing the caregiving budget. Our results align with those of previous studies, suggesting that some people desire control over budgets to gain more choice and flexibility in spending, while others dislike managing money and prefer leaving these administrative duties to third parties (McCaffrey et al., 2015). We further found that concerns about financial abuse influenced participants' preference for administering budgets. Some respondents preferred to manage their budgets to curb the improper use of budgets for agencies' profit. Such risk of exploitation in China is ascribed to the ambiguity and opacity of eligibility criteria and benefit amounts (merely stipulating upper limits) in the recently established LTCI. The government should offer individuals sufficient information regarding personal budgets and support their decision-making if it allows people to choose budget managers.

Additionally, our findings indicate that empowering older adults with flexibility in selecting care-related goods can help meet their individualized needs. Prescribing a catalog of goods is unresponsive and ineffective in allocating benefits because people are forced to acquire items prescribed by the government rather than what they demand or want (McCaffrey

et al., 2015). Furthermore, our findings demonstrate that one of the barriers to exercising consumer direction is the limited choices of goods suppliers. The stringent regulation on care-related goods prohibits people from choosing accessible and cost-effective options, which is a problem rarely emphasized in practice or in the existing literature. Governments could enhance consumer direction by providing older adults with more options and greater flexibility in choosing care-related items and goods providers.

Adequate and equitable budgets facilitate CDC. Without sufficient resources, older persons cannot afford formal care and must accept the only option available: relying on low-paid or unpaid family members (Kan & Chui, 2021). Adequate financial support is necessary to grant genuine choices to LTCI recipients and to ensure that CDC is a preference rather than the “forced option,” wherein they hire low-paid family members and internalize care costs within the family. These passive choices cannot be considered as CDC. Our interviews also suggest that the comparison group or reference group adopted by older adults affects their subjective evaluation of CDC policies, with urban or rural residents often comparing their benefit amounts to urban employees. As they receive lower benefits than urban employees, urban or rural residents perceive this welfare gap as perpetuating inequality rather than empowering these vulnerable groups with consumer direction. Policymakers should allocate sufficient and equitable budgets to older persons and family members, especially for urban or rural residents, which can ultimately empower them to freely choose among service options and narrow the gap in welfare support.

While prior literature has shown that clients demand information and support (Kan & Chui, 2021; Zhang et al., 2023), our findings suggest that clients and family members hold different attitudes about such information and support. Many of the older clients interviewed for the study knew little and showed no interest in learning about home-based services, whereas family members indicated their need for information provided by credible parties.

One reason for this difference is likely that information is critical for family members as they often navigate service options and determine whether and how to use home-based services. These results suggest that promotional materials should cater to two different audiences. Family members may demand more in-depth and comprehensive program information, while simple and straightforward information is more suitable for older adults. When both parties have knowledge about the program, care decisions can be made that balance the interests and preferences of clients and their family members. Dissemination of more extensive program information, especially through existing local administrative channels, such as the residents' committees, can ensure that LTCI information reaches the necessary populations.

Finally, family caregivers expressed a need for more training in caregiving skills so that they could tailor their services to meet older relatives' specific needs. Currently, the government provides minimal and standardized training, which fails to meet the individualized needs of older people. Our results suggest that governments could enhance CDC by providing a wider range of training programs about caring for older people and permitting participants to choose based on individualized needs.

Our findings have multiple theoretical implications. First, this study shows how CDC can be implemented in collectivist societies where family welfare takes precedence over clients' preferences. Future research on CDC policies could investigate strategies to balance clients' and family members' preferences and interests in a collectivist culture. Second, this study uncovers nuances in the process of making decisions regarding the utilization of home-based services. In a collectivist context, family members often make decisions for clients who are not aware of the services. Future studies about care-related decisions could acknowledge that clients do not always act as independent or self-determining agents and examine their expectations during the decision-making process. Is the apparent client apathy in acquiring care information and making decisions a result of (1) limited cognitive capacity, (2) social

acceptability bias leading to reluctance in expressing preferences conflicting with their family members' preferences, (3) the phenomenon of learned helplessness rather than an active choice to renounce their agency during the aging process, or (4) something else?

Our findings have practical implications for governments to enhance CDC policies according to personalized preferences. The results of our Guangzhou study can offer valuable lessons for other cities in China and many middle-income countries that are currently developing long-term care policies to meet individualized needs. As governments worldwide have been shifting funding for long-term care from institutions to home-based services, consumer direction is a major policy instrument that provides tailored and responsive services and helps older persons remain in the community. To enhance consumer direction, policymakers in China should develop and improve policy strategies based on the two themes identified in our study. These directions are also applicable to policymakers in any society operating CDC programs so they could leverage these instruments to promote consumer direction.

Limitations

This study has limitations. First, the transferability of the study findings to other contexts or individuals may be limited. Due to the limited number of older clients participating in this study, the findings were primarily shaped by family members' perspectives. People who agreed to participate may be more satisfied with services and affected by social acceptability bias, which provide a limited range of responses in the interviews. The findings may not be generalizable to the entire population using public home-based services in Guangzhou. Second, due to time and resource constraints, we did not perform member-checking with participants. However, to enhance credibility, we used a second analyst who was not involved in the interview process to independently code the transcripts and review the findings. To improve the confirmability and dependability of our findings, the team met

weekly throughout data collection and analysis and kept an audit trail outlining study decisions, such as sampling and coding decisions. Finally, despite the finding that family members' welfare overrides older people's preferences in Guangzhou, it does not necessarily suggest that this misalignment is unique to collectivist cultures or more prevalent in collectivist contexts than in individualistic cultures. Future research could investigate which cultural contexts are more likely to experience this incongruence and have detrimental consequences, as well as explore relevant strategies to address this issue. Despite these limitations, this is the first study to explore the CDC policy preferences of older people and family members living in a collectivist society.

Conclusion

Though consumer direction originates from individualistic cultures, people in collectivist societies also desire autonomy and flexibility in receiving services. However, family members' welfare might override older clients' preferences in collectivist cultures because consumer direction conflicts with family direction. Policymakers could leverage our findings to improve and implement CDC policies.

References

- Abdul Karim, S., Eikemo, T. A., & Bambra, C. (2010). Welfare state regimes and population health: integrating the East Asian welfare states. *Health Policy, 94*(1), 45-53. <https://doi.org/10.1016/j.healthpol.2009.08.003>
- Abrahamson, P. (2018). East Asian welfare regime: obsolete ideal-type or diversified reality. In K. H. Mok & S. Kühner (Eds.), *Managing Welfare Expectations and Social Change* (pp. 90-103). Routledge.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>

- Campbell, J. C., Ikegami, N., & Gibson, M. J. (2010). Lessons from public long-term care insurance in Germany and Japan. *Health Affairs*, 29(1), 87-95.
<https://doi.org/10.1377/hlthaff.2009.0548>
- Chen, L. (2017). Power and ambivalence in intergenerational communication: Deciding to institutionalize in Shanghai. *Journal of Aging Studies*, 41, 44-51.
<https://doi.org/10.1016/j.jaging.2017.03.004>
- Choi, Y. J. (2007). *Coming to a standstill: A new theoretical idea of East Asian welfare regimes*.
<https://www.spi.ox.ac.uk/files/barnettpaper20073yjcpdf>
- Christensen, K., & Pilling, D. (2014). Policies of personalisation in Norway and England: On the impact of political context. *Journal of Social Policy*, 43(3), 479-496.
<https://doi.org/10.1017/S0047279414000257>
- Da Roit, B., & Le Bihan, B. (2010). Similar and yet so different: cash-for-care in six European countries' long-term care policies. *The Milbank Quarterly*, 88(3), 286-309.
<https://doi.org/10.1111/j.1468-0009.2010.00601.x>
- Da Roit, B., & Le Bihan, B. (2019). Cash for long-term care: Policy debates, visions, and designs on the move. *Social Policy & Administration*, 53(4), 519-536.
<https://doi.org/10.1111/spol.12506>
- Ferrero, I., Guitián, G., & Sison, A. J. G. (2016). Human Dignity and The Dignity of Work: Insights from Catholic Social Teaching. *Business Ethics Quarterly*, 26(4), 503-528.
<https://doi.org/10.1017/beq.2016.18>
- Fung, H. H. (2013). Aging in culture. *The Gerontologist*, 53(3), 369-377.
<https://doi.org/10.1093/geront/gnt024>
- Goodman, R., & Peng, I. (1996). The East Asian welfare states: Peripatetic learning, adaptive change, and nation-building. In G. Esping-Andersen (Ed.), *Welfare States in Transition: National Adaptations in Global Economies* (pp. 192-224). Routledge.

- Hengelaar, A. H., van Hartingsveldt, M., Wittenberg, Y., van Etten-Jamaludin, F., Kwekkeboom, R., & Satink, T. (2018). Exploring the collaboration between formal and informal care from the professional perspective—A thematic synthesis. *Health & Social Care in the Community*, 26(4), 474-485. <https://doi.org/10.1111/hsc.12503>
- Jones, C. (1990). Hong Kong, Singapore, South Korea and Taiwan: Oikonomic Welfare States. *Government and Opposition*, 25(4), 446-462. <http://www.jstor.org/stable/44482535>
- Kan, W. S., & Chui, E. (2021). Vouchers and consumer-directed care: Implications for community care services in Hong Kong. *The British Journal of Social Work*, 51(1), 96-113. <https://doi.org/10.1093/bjsw/bcaa158>
- Kramer, B. J., Boelk, A. Z., & Auer, C. (2006). Family conflict at the end of life: Lessons learned in a model program for vulnerable older adults. *Journal of Palliative Medicine*, 9(3), 791-801. <https://doi.org/10.1089/jpm.2006.9.791>
- Ma, Z. (2021). Affect, sociality, and the construction of paternalistic citizenship among family caregivers in China. *HAU: Journal of Ethnographic Theory*, 11(3), 958-971. <https://doi.org/10.1086/717516>
- Mahoney, K. J., Simon-Rusinowitz, L., Loughlin, D. M., Desmond, S. M., & Squillace, M. R. (2004). Determining personal care consumers' preferences for a consumer-directed cash and counseling option: Survey results from Arkansas, Florida, New Jersey, and New York elders and adults with physical disabilities. *Health Services Research*, 39(3), 643-664. <https://doi.org/10.1111/j.1475-6773.2004.00249.x>
- McCaffrey, N., Gill, L., Kaambwa, B., Cameron, I. D., Patterson, J., Crotty, M., & Ratcliffe, J. (2015). Important features of home-based support services for older Australians and their informal carers. *Health & Social Care in the Community*, 23(6), 654-664. <https://doi.org/10.1111/hsc.12185>

- Mönkediek, B., & Bras, H. (2014). Strong and weak family ties revisited: reconsidering European family structures from a network perspective. *The History of the Family*, 19(2), 235-259. <https://doi.org/10.1080/1081602X.2014.897246>
- Moran, N., Glendinning, C., Wilberforce, M., Stevens, M., Netten, A. N. N., Jones, K., Manthorpe, J., Knapp, M., Fernández, J.-L., Challis, D., & Jacobs, S. (2012). Older people's experiences of cash-for-care schemes: Evidence from the English Individual Budget pilot projects. *Ageing and Society*, 33(5), 826-851. <https://doi.org/10.1017/s0144686x12000244>
- Nakagawa, T., Jopp, D. S., Gondo, Y., Lehrfeld, J., Rott, C., & Oswald, F. (2018). Valuation of Life Among Old and Very Old Adults: Comparison Between Germany and Japan. *Innovation in Aging*, 2(2), igy020. <https://doi.org/10.1093/geroni/igy020>
- Ottmann, G., Allen, J., & Feldman, P. (2013). A systematic narrative review of consumer-directed care for older people: Implications for model development. *Health & Social Care in the Community*, 21(6), 563-581. <https://doi.org/10.1111/hsc.12025>
- Parkinson, K., Pollock, S., & Edwards, D. (2018). Family group conferences: An opportunity to re-frame responses to the abuse of older people? *The British Journal of Social Work*, 48(4), 1109-1126. <https://doi.org/10.1093/bjsw/bcy048>
- Sciegaj, M., Capitman, J. A., & Kyriacou, C. K. (2004). Consumer-directed community care: Race/ethnicity and individual differences in preferences for control. *The Gerontologist*, 44(4), 489-499. <https://doi.org/10.1093/geront/44.4.489>
- Steiner, A., McMillan, C., & Hill O'Connor, C. (2022). Investigating the contribution of community empowerment policies to successful co-production- evidence from Scotland. *Public Management Review*, 1-23. <https://doi.org/10.1080/14719037.2022.2033053>

- Wada, Y. (2015). Older people's exercising of choice in long-term care: A comparative analysis of England and Japan. *Ageing and Society*, 36(06), 1185-1210. <https://doi.org/10.1017/s0144686x15000264>
- Zhang, J., Chen, Y.-C., Shi, C., & Wang, J. S.-H. (2023). Developing an Operationalized Framework for Comparing Consumer-Directed Care for Older Adults: Evidence from Expert Survey and Cross-National Comparison. *Journal of Aging & Social Policy*, 1-21. <https://doi.org/10.1080/08959420.2023.2297594>
- Ziliotti, E. (2022). Questions for Hierarchical Confucianism. *The Review of Politics*, 84(3), 329-349. <https://doi.org/10.1017/S0034670522000304>

Table 1
Participant Characteristics (n = 24)

Characteristics	Older Client (n = 6)	Family member (n = 18)
Gender		
Female	3	10
Male	3	8
Age in years		
< 60	-	11
60-84	3	5
≥ 85	3	2
Education attainment		
Illiterate	2	-
Below high school	3	11
High school or above	1	7
Living arrangement of client		
Only living with spouse	1	5
Living with others	5	13
Client with dementia		
No	6	11
Yes	-	7
Client benefit type		
Urban employee	4	11
Urban/rural resident	2	7
Service model		
CAC user	2	5
CDC user	4	13
Relation with clients		
Spouse	-	6
Adult child	-	11
Sister	-	1