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Why are people with dementia overlooked in long-term care insurance policy in Guangzhou, China?

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Abstract

Background and objectives There is a growing demand for dementia care to be funded by long-term care insurance (LTCI). However, evidence indicates that people with dementia are overlooked in China's LTCI policy and empirical research on this issue is notably scarce. Among the first seven LTCI pilot cities that officially enrolled people with dementia, Guangzhou is unique for roll-back LTCI policies related to eligibility criteria and benefits. This study aims to explore why people with dementia are overlooked in China's LTCI policy, using Guangzhou as a case study.

Methods Semi-structured interviews were conducted with stakeholders involved in LTCI need assessment and care delivery in Guangzhou. Eight LTCI assessment specialists, 22 formal caregivers, and six informal caregivers were interviewed from December 2021 to October 2022. Data was analyzed using NVivo 11.0 software and the Gilbert welfare framework to identify themes.

Results Interviewees reported that need assessment lacked a clear definition, were poorly supervised, and had high moral hazards. Challenges to care delivery included unprofessionalism of formal caregivers, shortage of resources, unprepared informal caregivers, a lack of a supportive environment and the negative impact of COVID-19.

Discussion and implications People with dementia are overlooked in LTCI policy which may result from difficulties in implementing dementia-related assessment criteria, and hampered service delivery due to a shortage of skilled caregivers. These issues need to be carefully considered before scaling up the coverage of LTCI policy nationwide.

Keywords Dementia, Long-term care insurance, Long-term care, China

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Introduction

In China, an estimated 15 million people are living with dementia [1], increasing to 49 million in 2050 [2]. Alongside the soaring number of people with dementia, the associated medical and social care cost is projected to exceed $372.3 billion by 2050 [3]. What's worse, the majority of people with dementia do not receive any post-diagnostic care [4]. Formal care (i.e. care delivered at home, in community settings, and in institutions by paid professional staff) for people with dementia is insufficient in China, while family members still act as the main caregivers [5]. Prior research from Korea and France indicates that public long-term care insurance (LTCI) can reduce overall lifelong medical expenses of individuals with dementia, encourage the use of professional care services, and ease the burden on informal caregivers [6, 7]. Thus, the widening gap between growing need for dementia care and dwindling family size could be filled by adequate financial and services funded by LTCI [8].

To ease the financial burden of affording care services, the central government of China announced its first document on piloting LTCI in 2016. Citizens who bore the responsibility of paying social insurance and met the enrollment criteria could enjoy long-term care services. An initial 15 cities and two provinces were chosen to explore their locally initiated pilot scheme, each varying in target groups, eligibility criteria, and benefit scopes [9]. An additional 14 pilot schemes were added in 2020 [10]. As part of an effort to narrow the variation, a national standard on need assessment that all piloted cities are required to follow in the next two years was introduced in 2021, but it merely focused on physical disability, overlooking cognitive disabilities of people with dementia. By March 2022, the number of beneficiaries was exceeding 1.72 million. In the process of introducing a national model to meet the diverse needs of beneficiaries in a country with a vast population and geographical variation, the central government decided to steer the pilot cities towards a unified policy direction rather than further innovating in their own way [11].

Although the shift in LTCI coverage from solely population with disability to including both people with disability and people with dementia is a potential trend, reflected in the proactive approach taken by countries like South Korea and Japan long ago [12, 13], China is wavering. In the Chinese LTCI policy, people with dementia are identified through clinical diagnosis of dementia or cognitive assessment combined with having difficulties in activities of daily living in the LTCI schemes. Due to varying classification criteria, this study defined the inclusion of dementia groups in LTCI coverage based on the incorporation of dementia groups in the coverage criteria, assessment standards, or care service provisions. Of the initial 15 cities, only seven (i.e. Guangzhou, Nantong, Chengdu, Qingdao, Shanghai, Shangrao, and Suzhou) officially included people with dementia as beneficiaries in their LTCI coverage until June 2023 [14, 15]. However, LTCI schemes related to dementia remain vague [16, 17]. Cognitive assessment standards varied: Qingdao and Nantong use the mini-mental state examination to assess cognitive status, while the other five cities include only a few cognitive measures in their assessment [14]. Variation in assessment standards further leads to unclear enrollment criteria, with Qingdao and Chengdu enrolling only severe dementia cases, while Nantong and Shangrao enroll moderate-to-severe cases [15].

Among LTCI pilot cities enrolling people with dementia, Guangzhou shows uniqueness in its rollback of LTCI policies related to people with dementia over three rounds (Fig. 1). Guangzhou officially started its LTCI policy in August 2017 and enrolled people with dementia using assessments including the Barthel scale [18] (measuring independence in performing activities of daily living) and/or diagnosis of dementia. In 2019, cognitive training, occupational therapy, and dementia care were added to the list of available services [19]. Subsequently, in 2021, more comprehensive assessment scales were introduced, including a mental status assessment scale, and people with dementia were specifically identified as a population for inclusion. However, as the scheme progressed, several issues emerged. In early 2022, dementia was removed as a separate category from the eligibility criteria, and LTCI coverage shifted to a broader focus on people with disability, including those with disability due to cognitive impairment [20].

Besides changing eligibility criteria, complexity also exists in dementia care delivery. Among the pilot cities, only Qingdao, Nantong, Chengdu and Guangzhou lay out an optional services list for people with dementia. The services provided in LTCI for people with dementia include basic daily activities such as eating, cleaning, and dressing; and special care such as prevention of loss and aggressive behavior, and maintenance of orientation. As care is delivered through a service package, differences between programs for disability and dementia services have diminished [21]. Due to the complexity of dementia care services and the inadequate preparation of the LTCI system [22], the current long-term care system in China has yet to meet the care needs of people with dementia, particularly during the COVID-19 pandemic over the last three years [23].

Identified research gaps included the need for an evidence-based dementia-specific practice model and policy gaps included insufficient health services frameworks for dementia-inclusive practice [24]. Current research on dementia in China's LTCI policy is notably

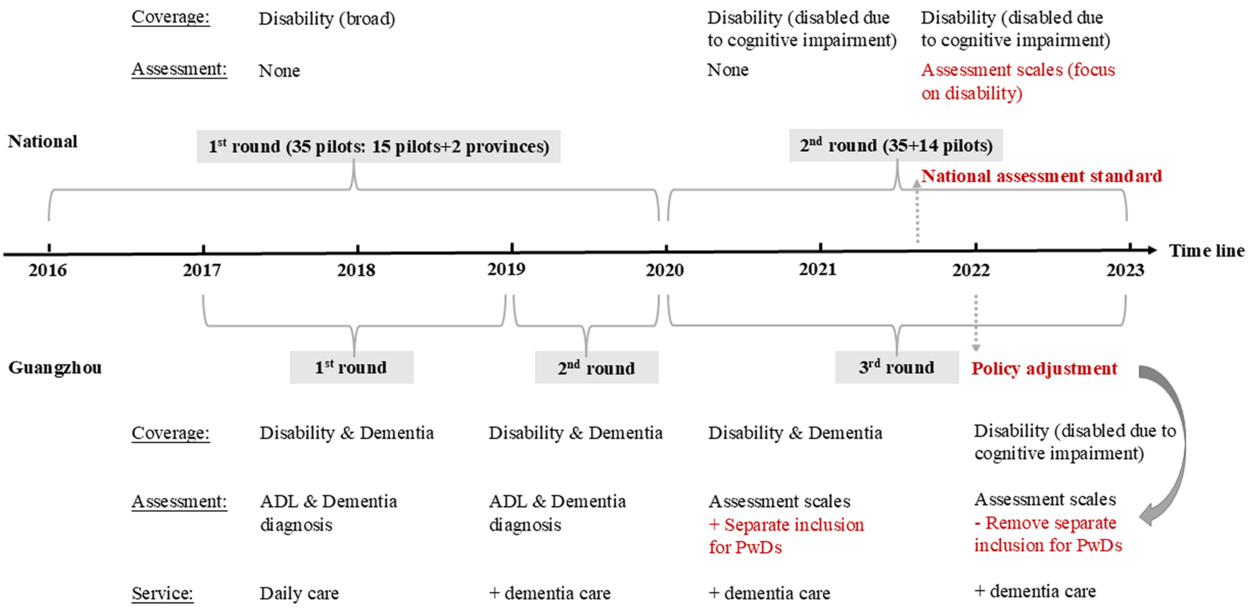

Fig. 1 The national two-round long-term care insurance policy corresponds to Guangzhou three-round long-term care insurance policy

limited, with only a few theoretical studies analyzing the dementia policies of various pilot programs and scarce empirical research [14]. As one of the most developed cities and one of the earliest LTCI pilot cities in China, Guangzhou's unique rollback of LTCI practice related to dementia from 2017 to 2022 exemplifies the challenges in implementing dementia care, providing valuable insights for enhancing dementia care and for pilot cities seeking to include the dementia population to coverage. Therefore, this study aimed to explore reasons for overlooking people with dementia in China, by examining Guangzhou's LTCI policy. Gilbert social welfare policy analysis framework is a representative framework suitable for the evaluation and problem analysis of LTCI pilot policies [25]. The framework includes four basic dimensions: allocation, benefits, delivery system, and finance [26]. Focusing on the allocation and delivery system dimensions, qualitative interviews were conducted with assessment specialists (ASs), formal caregivers (FCs) and informal caregivers (ICs) involved in LTCI need assessment and care delivery to better reveal the challenges facing these two segments. Our findings would draw attention to the needs of people with dementia and facilitate tailored design for dementia care support in LTCI, both domestically and internationally.

Methods

Study design

This study, conducted in Guangzhou from December 2021 to October 2022, used semi-structured interviews to elicit stakeholders' perspectives on the current state of LTCI implementation and the challenges in LTCI need assessment and care delivery. Semi-structured interviews were chosen over focus groups to allow participants to speak freely [27], a method previously used in LTC research [28] and caregiving for older adults in China [29, 30].

Ethical approval was obtained from the Institutional Review Board of Sun Yat-sen University (IRB Approval no. 2019–124) and UCL Research Ethics Committee (REC Approval no. 21679.001), with informed consent from all participants.

Study sample

Three groups of stakeholders were sampled and invited to participate, namely ASs, FCs, and ICs. Figure 2 shows the relationship of stakeholders providing dementia care under the LTCI policy. Their inclusion criteria were,

(1) ASs: Worked at three major assessment agencies and received training in LTCI assessment.
(2) FCs: Paid nursing staff who were employed by 12 care agencies, located in five central administrative districts (i.e. Yuexiu, Liwan, Tianhe, Huangpu, Zengcheng), based on the list of designated LTCI care agencies in Guangzhou released by the Healthcare Security Administration [31].
(3) ICs: According to the regulations of the Guangzhou government, caregivers, including family members and domestic helpers, trained and certified by Guangzhou's government, substitute the shortage of formal caregivers. These ICs receive a monthly

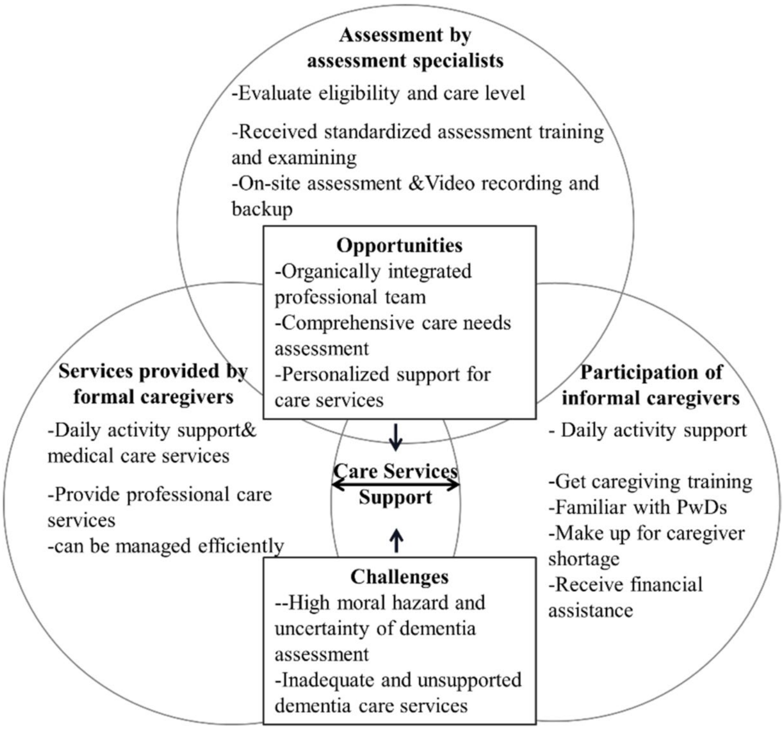

Fig. 2 Stakeholder relationship map for dementia care in long-term care insurance policy. *Note.* LTCI = long-term care insurance; PwDs = people with dementia. Assessment specialist: These professionals work in tertiary hospitals or commercial insurance companies, and are trained by the Guangzhou Healthcare Security Administration. They have qualifications to assess LTCI level. Formal caregivers: Formal caregivers are caregivers who work for care agencies and can provide care in both institutional and home settings. Informal caregivers: Beneficiaries' family members or domestic helpers may apply as informal caregivers for in-home care only. They provide care services for older individuals under the management of care agencies and receive wages

subsidy of 2,000 yuan from the care agencies, which is lower than the salary of FCs. The government in Guangzhou set up a local mechanism that pays the family member who provides care and nominally works a as freelance care worker for a service supplier. As some families already hiring domestic helpers to provide care, this policy applies to both family members and domestic helpers. Given conducting interviews with people with dementia is difficult to implement, and interviews with stakeholders are sufficient to reflect the needs of people with dementia, people with dementia were not included in the study sample.

ASs were invited to participate through cluster sampling. FCs were invited in designated agencies in designated districts. If participation was refused, they were replaced with same-district and same-type agencies. ICs were recruited from a representative care agency via purposive sampling.

Data collection

Based on the Gilbert framework of social welfare policy analysis, we designed the interview outline. Semi-structured interviews were conducted following interview guides specific to each stakeholder group (Appendix Table 3), with a focus on the practice of need assessment and care delivery in LTCI. For each, interviews focused on:

1. ASs: LTCI eligibility and care level for people with dementia
2. FCs: provision of formal dementia care services (in institutions / at home) and in-home care training, and
3. ICs: provision of informal dementia care services and receipt of in-home care training.

Interviews, lasting 45–90 min, were conducted by two researchers: 1) a moderator who was responsible for asking questions and situational control, and

2) an observer who captured and noted interviewees' behaviors.

The sample size was determined by the theoretical point of data saturation. Specifically, when the number of pre-designed interviews was completed, rich interview content was collected, and there was no new content in the last few interviews, the data saturation point was considered to be reached.

Half of interviews were conducted online using Tencent Meeting due to COVID-19. Entry to the meeting was password-protected to protect the identity of participants. Interviews were recorded and informed consent was obtained beforehand. Explanations were provided on study aims and procedures, and ample opportunities were given for clarification and the right to withdraw. Interview data was stored on a password-protected document, only accessible to authors BY and ZYZ. Preview fieldwork supplemented the interviews, which enriched the understanding of institutional context.

Data analysis

Interviews were recorded, transcribed verbatim in Chinese, and translated into English by two researchers (BY, ZYZ). Transcripts were analyzed using NVivo 11.0 software and the Gilbert welfare framework to identify themes [32].

The framework is widely used in social welfare policy research, encompassing allocation, delivery, provision, and financing of social systems, each with corresponding contents [25]. Social allocation involves welfare eligibility and is contingent on specific conditions. For example, people living with disability (people with dementia included) are eligible for LTCI services only if they are graded as requiring care, categorized into 5 levels from 1 (mild disability) through 5 (severe disability). Welfare delivery deals with organizational arrangements between service providers and beneficiaries. Care services in LTCI can take place inside a nursing home or at home. Welfare provision involves types of benefits, such as cash transfers or in-kind assistance. Financing of social systems involves taxation, fees, and donations, among other sources of revenue. This study focused on allocation and delivery aligned with study objectives, and coded themes under two dimensions of assessment and care delivery.

The study rigor was ensured by careful applications of the study transparency, credibility and dependability [33]. Transparency was achieved by clearly describing the research procedures. Credibility was ensured by maintaining detailed records and presentation of the data. Two authors (BY, ZYZ) independently coded the data to generate the initial themes, and then reviewed the themes identified. When differences arose, the research team of four team members discussed to achieve consensus.

Results

Thirty-six participants (8 ASs, 22 FCs, and 6 ICs) participated in the study, with an average of two years experience in LTCI need assessment or care delivery. 24 (66.7%) of participants were female. Participant characteristics are outlined in Table 1. Three assessment agencies and 12 care agencies were included in the final results.

Of the 12 care agencies, half reported numerous challenges in providing dementia-related care services based on the latest eligibility criteria that no longer enrolled people with dementia as a separate category. Challenges were classified into two major themes: (1) Need assessments were unclear and poorly supervised, with high high-moral hazard, and (2) care delivery for people with dementia was inadequate and unsupported. Table 2 reports the main study findings.

Challenges in LTCI need assessment for people with dementia

Complexity of dementia assessment

ASs indicated their inadequate expertise in dementia assessment. Their limited knowledge proved difficult in conducting professional dementia assessments and resulted in a greater reliance on certificates of dementia diagnosis or medical records for LTCI assessment. The complex range of dementia-related symptoms, and varying severity, makes it difficult to create a full picture in an interim assessment and recognize inconsistencies when older adults' symptoms do not match the common symptoms of dementia.

> *"The assessment specialists came from different departments, not always from psychiatric or memory clinics, and rarely had expertise in dementia." (AS 1)*

> *"If we perceived symptoms of dementia but without proof like diagnosis, we couldn't identify it. Mild dementia sometimes couldn't be found in the assessment, but was obvious in daily life. It was hard to tell when he acted normal." (AS 6)*

Interviewees also reported a higher risk of moral hazard and fraud involved in dementia assessment than in disability assessment. In social welfare policy, moral hazard refers to the tendency for individuals to change their behavior when provided with protection or benefits, potentially increasing risks or misusing resources. According to the Healthcare Security Administration website [34], beneficiaries with both disability and dementia are eligible to receive more LTCI services,

Table 1 Sociodemographic characteristics of study participants

Assessment specialist (AS)

No	Gender	Years of working
AS1	Female	3
AS2	Female	3
AS3	Male	1
AS4	Female	2
AS5	Female	1
AS6	Female	2
AS7	Male	4
AS8	Male	2

Informal caregivers (IC)

No	Gender	Years of caring
IC1	Female	2
IC2	Female	2
IC3	Female	1
IC4	Female	2
IC5	Male	1
IC6	Male	< 1

Formal caregiver (FC)

No	Gender	Years of working	Agency	Service type
FC1	Male	2	Agency 1	Institutional & Home care
FC2	Female	2		
FC3	Male	5	Agency 2	Institutional care
FC4	Female	3		
FC5	Female	4		
FC6	Male	< 1	Agency 3	Institutional & Home care
FC7	Female	< 1	Agency 4	
FC8	Male	2	Agency 5	Home care
FC9	Female	2		
FC10	Male	2	Agency 6	
FC11	Male	1		
FC12	Female	4	Agency 7	
FC13	Female	4		
FC14	Female	4	Agency 8	
FC15	Female	2		
FC16	Female	3	Agency 9	
FC17	Female	3		
FC18	Female	2		
FC19	Male	2	Agency 10	
FC20	Female	2	Agency 11	
FC21	Female	2	Agency 12	
FC22	Female	< 1		

Table 2 Challenges identified in long-term care insurance assessment and delivery for people with dementia

Component	Theme	Content
Need assessment	Complexity of dementia assessment	Inadequate expertise in assessment
		High moral hazard
	Restrictive assessment criteria	Inequitable benefits
	Difficulties in evaluating regulation	Lack of restrain to insurance fraud
		Lack of inspection of care level
Care delivery	Unprofessionalism	Aversive behaviors
		Cream-skimming behaviors
	Shortage of care resources	Lack of formal caregivers
		Lack of care training
	Unprepared informal caregivers	Poor receptivity to training
		Unsuitable training
		Insufficient awareness
	Lack of supporting environment	No specialized area and services
		Lack of professional equipment
	Negative impact of COVID-19	Loss of caregivers
		Poor access to outside resources

including services for a longer time, and more reimbursement for care agencies. For informal caregivers, being registered in and employed by care agencies allowed them to receive additional caregiver allowance. Almost every AS interviewed reflected that this creates an opportunity for "insurance fraud" when informal caregivers or beneficiaries falsely claim to have dementia in their assessment, or medical institutions may help to submit false dementia diagnoses.

> *"The policy and eligibility criteria were available on the website, and agencies would teach older adults how to get higher care levels. Some agencies even paid medical institutions money for false diagnoses" (AS 1)"*

> *"Family members would mislead you, saying that he couldn't do anything, like eat by himself, and the most outrageous thing was that he didn't know his name. (AS 4)*

Restrictive assessment criteria

In the policy adjustment in early 2022, the eligibility criteria became more restrictive and dementia was not considered separately anymore. The removal of the special provision for people with dementia caused those with mild dementia to be excluded from LTCI and those with moderate-to-severe dementia to be rated at the lowest level of need, equal to that of mild disability. For moderate or severe people with dementia with disability, they need more care services than those with the same level of disability, yet their specialized needs regarding dementia have not been considered since the policy adjustment, which may result in an inequitable provision of the benefit.

Claimants are re-evaluated every 12 months to confirm eligibility. Due to the restrictive assessment criteria, care providers reflected that many participants' care levels have been downgraded. People with dementia were particularly affected, many of whom were re-rated from level 3 (Severe disability) to level 1 (Mild disability) or 0 (Basically normal). This indicates that, to some extent, the assessed care levels may not accurately reflect their care needs.

> *"The new assessment criteria would no longer include "having dementia" as a provision for upgrading the LTCI level, but would instead focus more on people with disability." (AS 2)*

Inadequate governmental supervision

Inadequate regulation by the government has made the dementia assessment more challenging and made insurance fraud in Guangzhou rampant. But fraudulent beneficiaries in China do not have to pay additional costs, except for their insurance qualifications being cancelled out. ASs are given the responsibility of identifying the authenticity of dementia, which leads them to be extra cautious while assessing people with dementia.

> *"Once I received a tip and went there to identify, I saw that the beneficiary was able to go out walking and shopping alone perfectly fine. But at that time when we assessed, she was lying in bed and couldn't even move." (AS 2)*

Moreover, the assessment of the care levels for LTCI was poorly regulated. As the assessment was highly influenced by subjective evaluations and individual practices of ASs, the assessment basis is inconsistent. At the same time, the lack of unified regulations led to difficulties in supervision. ASs held different attitudes towards dementia assessment. Some prioritized dementia diagnostic evidence, deeming it easier to assess people with dementia than those with disabilities. Others based their judgments primarily on the daily lives of older adults, finding the process more difficult and time-consuming due to limited communication and cooperation.

> *"It was easier to assess, as long as he had the diagnosis, because I cared for someone like that… Although able to take care of himself, he still needed reminders, and dementia was irreversible." (AS 1)*

> *"There were no regulations. The reassessment would be done only if the beneficiary complained or did not accept the care level. It was more difficult to access, especially severe people with dementia where he may ignore you completely. So, we usually judged by what we observed and sometimes asked their families." (AS 2)*

Challenges in care delivery

Unprofessionalism of formal caregivers

FCs were reluctant to provide care to people with dementia and showed adverse feelings due to the effect of supporting people with dementia and the range of dementia-related symptoms, particularly in the advanced stages of people with dementia. Caring for functionally impaired people with dementia who can sometimes exhibit changed behaviors could be more taxing physically and emotionally for the caregivers. How caregivers understood and adopted dementia care affected their caregiving. Some interviewees said that the unpredictable emotions and behaviors of people with dementia made it difficult for caregivers to choose to provide dementia care.

> *"Caregivers were reluctant to care for the severe people with dementia who could be unpredictable, loud, combative, uncooperative and troublesome. I needed to remind him of everything, like defecating. This was much more difficult than caring for people with disability." (FCs, Agency 1)*

Shortage of care resources

There is cream-skimming behavior, defined as the risk selection of intentionally selecting or avoiding certain patients into services [35, 36], among care agencies and caregivers. Most long-term care services in Guangzhou are outsourced to private service providers, who keep costs as low as possible for the same revenue, for instance, extreme avoidance of public benefits services that had little or almost no profitability. Caregivers preferred to provide easier disability services, since dementia-related services were more time-consuming and difficult, but charged the same as disability services in LTCI. Fees charged by institutions specializing in caring for people with dementia outside of LTCI were much higher than LTCI fees.

> *"The dementia care services were set "when necessary" in the policy, it is optional. We could provide dementia care, but the pay was so low and not proportional to the time spent that nurses were reluctant to do it. For example, 40-min service was paid only ￥10 to ￥20 to care agencies." (FC 20, Agency 11).*

There was a shortage of FCs in institutions and they lacked the capacity to provide dementia-specific programs. The current staff-to-resident ratio in most institutions is insufficient (1:5.73 in Guangzhou) as people with dementia always need time-consuming general supervision and require a large amount of time, manpower and patience. FCs have very limited formal theoretical and practical training prior to employment and during their dementia care. Professional training in dementia care and psychological interventions for care workers was absent.

> *"New residents needed time to build trust, sometimes a month. For the first two months, we had to assign a caregiver to take care of him exclusively. After familiarization, one caregiver could look after three to five people with dementia simultaneously." (FC 4, Agency 2)*
>
> *"We had little understanding about dementia at school or at work. The training in the hospital was not systematic and unprofessional, more about medical than life care." (FCs, Agency 5, 9)*

Unprepared informal caregivers

From the perspective of FCs, ICs struggled to provide professional dementia care, even though they comprise the majority of caregivers. The training that ICs received was too general and repetitive to improve their caregiving significantly. ICs were poorly receptive to training. Where informal caregivers were family members, it was difficult for institutions to manage them as employees. When caregivers were domestic helpers, they often had lower literacy levels and had difficulty grasping the training materials.

> *"The training and certification for informal caregivers were superficial. If you demand too much of them, he/she would find you annoying. " (FC 8, Agency 5)*
> *"Many domestic helpers have little education. She may not know the words of the training material, so I usually read it to her." (FC 2))*

From the perspective of ICs, most of ICs lacked dementia care skills and relied more on the training provided by care agencies. However, the training was not tailor to their education level or needs. The training content was vague, and the availability and standards of dementia services training were not clear. The quality of training was uncertain, as reflected in the low frequency and short duration of training. Due to the COVID-19 pandemic, many training providers have canceled on-site training in favor of distributed training materials online, reducing regular formal interactions between ICs and FCs.

> *"The agency would remind you to do dementia care services, with text messages. But there were no specific instructions. The nurse or rehabilitator used to come to our home to teach us, e.g. massage training once a month, but there was no more during the pandemic."(IC 1, 5)*

Some family members were not aware of the care needs of people with dementia, believing dementia was a natural phenomenon associated with ageing, or that dementia was irreversible and dementia services were not effective. Many missed opportunities for care. As dementia worsens, it becomes increasingly difficult for people with dementia to cooperate with dementia services due to communication difficulties or physical disability.

> *"It was necessary when they were awake at early stage. But now they were too sick to cooperate, it was unnecessary." (IC 1).*
>
> *"Cognitive function training sound very profound, and no one taught or helped me. I just made sure she could eat, bathe, and not fall." (IC 3)*

Lack of supporting environment

Respondents also felt that most institutions lacked dementia-friendly resources. A separate dementia area in the institution and corresponding environment (layout, lighting, noise, color and signposting) were necessary due to the frequent wandering and possible aggressiveness of people with dementia. Regarding service programs, there was not much distinction between those for people with dementia and those with disabilities. The primary difference between care was the need for more patience and companionship of people with dementia. Most institutional services related to dementia care were underutilized and difficult to maintain. Because it requires people with dementia to come to the institution accompanied by a guardian, the long distance from the institution to the home, the low mobility of the patient, and the safety risks in the process of going out and serving have become the hindrance factors for people to choose this type of service.

> *"There were two types of institutions, some did not accept people with dementia… thought they may affect other older adults… the other dedicated one or two floors to people with dementia for easier management without affecting others." (FCs, Agency 1).*

> *"There was uncertainty about choosing to accompany or daycare, whether they provided lunch and what accidents may arise is unknown. People who lived far away would not come. Previous daycare offered services like finger exercises and also had sensory rooms, but it closed soon due to low utilization." (FCs, Agency 9,10)*

Negative impact of COVID-19

Public health interventions for the COVID-19 pandemic had multiple effects on long-term care work, including social isolation, visitor restrictions, and long-term institutional lockdowns. In this environment, neuropsychiatric and behavioral symptoms of people with dementia worsened according to FCs, intensifying the impact of supporting people with dementia. Mobility restrictions were also found to cause potential psychological problems or life imbalances for caregivers, and, in some cases, lead to a high turnover rate of caregivers.

> *"Many caregivers may be under more pressure during the lockdown period, or unable to balance family with work, so they may resign, and then it was hard to hire new employees immediately." (FC 7, Agency 4)*

It was also difficult to recruit new caregivers during the pandemic. Even if available, they required a transition period to adapt. The only facility that specialized in dementia care in our study reported that the frequency of dementia care services had been greatly reduced due to restrictions on movement and limited outside resources. Only a few services could be provided within the institution.

> *"Nine therapies, like intergenerational, communication, gardening. People with dementia used to be taken to the park every week by pet dog doctors, and kindergarteners came every month. But now, the frequency reduced, and it put much pressure on us if someone got infected." (FC 4, Agency 2)*

Discussion

Semi-structured interviews were conducted with 36 stakeholders (ASs, FCs and ICs) involved in LTCI need assessment and care delivery in Guangzhou. Interviews revealed several challenges that may explain the overlooking of people with dementia in Guangzhou's LTCI policy, as summarized in Fig. 2.

In the allocation dimension, high moral hazard might tend to be the biggest challenge in assessing dementia. This may be because of reliance on questionnaire-based assessment criteria of dementia or cognitive impairment, which cannot verify beneficiaries' cognitive function objectively. Since LTCI offers greater reimbursement for care services, along with increased subsidies for informal caregivers based on the care level of beneficiaries, it is not uncommon for care agencies, beneficiaries, and their informal caregivers to seek higher levels of assessment to gain greater financial support [21]. Moral hazards associated with LTCI assessment are less prominent in Japan and South Korea, whose benefits do not involve potential financial gains, but solely the provision of care services [37]. Japan and South Korea clarify inclusion criteria for people with dementia by the mini-mental state examination scale [38], similarly in Germany, eligibility is assessed through a thorough examination including cognitive and communication abilities, behavior and mental health modules [39]. While Japan and South Korea clearly differentiate beneficiaries' physical and cognitive disabilities, Germany is gradually losing the distinction between cognitive and physical disability by simplifying eligibility categories and introducing benefits for people with cognitive impairment [40].

For the delivery dimension, caring for people with dementia is challenging, particularly due to the insufficient number of FCs and poor professional knowledge of dementia. In China, there is a considerable shortage of FCs, with over 50 million people with physical disability and people with dementia in need of care, but only around 322,000 trained FCs available [41]. Dementia care requires more caregiving than just physical disability due to behavioral and psychological symptoms, including but not limited to agitation, aggression, psychosis, catastrophic reactions, waking at night, and communication disorders [19]. To meet these care needs, special services are required, which are barely fulfilled by current psychiatric personnel in China [42]. Guangzhou has yet to develop a workforce of specialized dementia care nurses, and most FCs lack dementia care skills [43]. Nurse training syllabi are short of modules on dementia, leading to students' poor knowledge and skill about dementia care [44]. There is also next to no training for dementia care when working in the care service [45]. The majority of frontline FCs are middle-aged females with limited education and poor caregiving skills [46], as caregiving jobs are poorly paid, with low social status and satisfaction. Complex demands of people with dementia beyond FCs capacity, without sufficient supervision for care service in delivery, may render aversive and cream-skimming behaviors.

Our findings further reveal poor awareness and inadequate knowledge of family caregivers for people with dementia. Families mainly take care of their older relatives with dementia, but their caregiving quality is hindered by a limited understanding of the disease as it progresses [5]. Influenced by the culture of filial piety and subsidies available, family caregivers may prefer home care over institutional care [47]. Essential dementia knowledge and home-based caregiving skills, such as safety, rehabilitation, and stress management strategies, are urgently needed [48]. However, no clear training for informal caregivers exists in national policies [49]. Guangzhou's informal caregiver training remains underdeveloped, let alone training tailored for dementia care. Previous studies have shown that family caregivers of people with dementia receive minimal external support in psychological assistance, respite services, and information access [30]. The limited functionality of communities results in a significant lack of social support for informal caregivers, which has worsened since the onset of COVID-19 [50].

Implications for LTCI

If the national policy of China, expected in the next one or two years, continues to overlook the complex care needs of people with dementia, families will continue to bear the burden alone. Urgent action is required to address this gap in the piloted LTCI schemes.

Proper incentives for care providers are crucial. Care providers will integrate dementia care into care packages if a separate need assessment for dementia is introduced and dementia care services are duly included on the LTCI reimbursement list, similar to Japan and Korea. Additionally, a practical regulatory framework for LTCI [51]. Specifically, in the need assessment, consistent assessment criteria need to be developed to ensure the accuracy of the LTCI level. At the same time, the punishment measures for the fraudulent beneficiaries should be formulated, and the supervision of insurance fraud should be strengthened. In terms of care delivery, there is a need to monitor caregivers' choices and care services, in particular aversive behaviors and cream-skimming behaviors, to assess professionalism.

Establishing a practical service standard, such as providing cognitive training and functional maintenance to prevent falls and burns, can enhance dementia care efficiency. Training caregivers in dementia care knowledge and skills can also help them better understand dementia-related behaviors and improve care quality [52]. Including dementia-related content in medical and nursing curricula in China is essential. The Healthcare Security Administration should organize regular, on-site, high-quality training sessions for caregivers. Norms for dementia care units have been introduced in Qingdao, Shanghai, Nantong, and Chengdu and should be expanded to all pilot cities [14].

In the post-epidemic period, the emotional and social needs of people with dementia must be addressed in real time. Both caregivers and older adults need preventive measures for protection and tailored care services. Future reforms should focus on supporting caregivers with a resourceful, informative, and knowledgeable system. Such a system should integrate multidisciplinary and collaborative care teams, including general practitioners, caregivers, social care workers, and volunteers [38]. Creating dementia-friendly environments by setting up dementia zones in care facilities, raising awareness of dementia among residents and reducing dementia discrimination in homes and communities, similar to Japan, should accompany these efforts [53, 54].

Strengths and limitations

This study selects Guangzhou as a typical case to explore the challenges of dementia care in LTCI, based on first-hand interview data from three types of stakeholders involved in the need assessment and care delivery. This targeted data collection offers a more focused perspective than previous studies, presenting a holistic view of the challenges from different interview groups.

However, the study has some limitations. First, policymakers were not included in the interviews and the role of government plays in policy changes was not considered. The LTCI policy process is complex, and through interviews with assessment specialists and caregivers, this study focuses more on the dilemmas in the implementation process. Future research could focus more on policymakers, considering their role in the formulation and revision of LTCI policies. Second, because the educational attainment of the participants is relatively sensitive, we did not collect this information. We used years of caring, which could reflect the level of understanding of dementia care and assessment to some extent. Additionally, some interviews were conducted online due to COVID-19, potentially affecting the quality of the data. We established professional relationships with interviewees in advance to build a trusting relationship as much as possible. Last, the findings may have limited generalizability. The diversity of demographic characteristics, economic level, and LTCI policies across China means the challenges discussed are specific to Guangzhou and may not represent other cities. Further study is needed to enhance the research findings.

Conclusion

This qualitative study suggests that the overlook of people with dementia in LTCI in Guangzhou may result from challenges related to need assessment and care service delivery for those with dementia. We identified unclear, high-moral hazard and poor supervision as the main challenges in the need assessment process. LTCI care delivery processes have been plagued by poor professionalism and shortage of FCs, unprepared ICs, and lack of a supporting environment, particularly since the onset of COVID-19. Policy incentives and support for the inclusion of people with dementia are essential. We suggest establishing practical standards for dementia care services, strengthening caregiver training for dementia care, and developing effective regulatory frameworks for LTCI.

Appendix

Table 3 Interview guide

For LTCI assessment specialist	
1	How long have you been involved in LTCI assessment work?
2	What has changed in the eligibility criteria in the third pilot policy phase (2021)?
3	What is the general need assessment process?
4	Are there any difficulties in the assessment process? If so, what are they?
5	What measures have been taken to ensure the authenticity of the assessment process and LTCI level?
6	How is the assessment for people with dementia different from that for people with disabilities?
7	Is it necessary for people with dementia to provide dementia diagnosis when applying for LTCI?
8	How far does the severity of dementia affect the LTCI level?
9	Do specialists have adequate skills to conduct dementia assessments?
10	Are the existing eligibility criteria sufficient to identify people with dementia who have care needs?
For LTCI formal caregiver	
1	How long have you been involved in the LTCI assessment process?
2	What has changed in your work in the third pilot policy phase (2021)?
3	What is the general care delivery process?
4	Are there any difficulties in the care delivery process? If so, what are they?
5	What percentage of people with dementia have you serviced? Do they have a diagnosis of dementia?
6	What are the differences in providing care for people with dementia compared to caring for people with disabilities?
7	Are there any special service plans for people with dementia? (e.g. daily care and medical care services)
8	What are the difficulties in providing care for people with dementia?
9	Do you have sufficient skills to provide dementia services? Have you received training?
10	Do you think it is necessary to set special services for people with dementia and provide these services?
For LTCI informal caregiver	
1	How long has the person with dementia you are caring for been receiving LTCI benefits?
2	What is the current LTCI level of the person with dementia you are caring for? Do you think it accurate?
3	Has the people with dementia had any visits to a psychiatric hospital or dementia clinic?
4	Is a diagnosis of dementia necessary for the assessment?
5	Do the assessors refer to your feedback on the people with dementia condition during the assessment?
6	Do you think the cognitive status of the people with dementia has a significant impact on LTCI level?

7	What are the current LTC services available to people with dementia? Who provides them?
8	Is there a dementia-related cognitive maintenance service?
9	Do the people with dementia cooperate with dementia services?
10	Do you think it is necessary for people with dementia to receive dementia care services?
11	Have you received any caregiving training? If so, can you briefly describe it?
12	Are you confident to perform caregiving skills received in training? Are they useful?
13	To what extent do the existing LTC services share the impact of supporting people with dementia?

LTCI long-term care insurance, *LTC* long-term care

Abbreviations

LTCI	Long-term care insurance
ASs	Assessment specialists
FCs	Formal caregivers
ICs	Informal caregivers

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Authors' contributions

B.Y.: conceptualization, methodology, formal analysis, principal investigator, writing – original draft, writing – review & editing. Y.X.X.: formal analysis, writing – review & editing. W.K.C.: methodology, principal investigator, supervision, project administration, writing–review & editing. Z.Y.Z.: principal investigator, formal analysis, writing – review & editing. S.L.R.: conceptualization, writing and editing. N.C.: conceptualization, writing–review & editing. E.J.B.: conceptualization, writing–review & editing, and funding acquisition. J.L.: conceptualization, methodology, writing – original draft, writing – review & editing and funding acquisition. All authors read and approved the final manuscript.

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Data availability

The interviewees' personal information has been anonymized. Data is available on request.

Declarations

Ethics approval and consent to participate

Ethical approval was granted by the Institutional Review Board of Sun Yat-sen University (IRB Approval no. 2019–124) and UCL Research Ethics Committee (REC Approval no. 21679.001). Informed consent was obtained from all study participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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