

Caregiving experiences of older-adult informal family caregivers for older adults with comorbid dementia and physical disability: A qualitative study using the caregiving stress-process model

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Abstract

Background

Against the backdrop of population aging in China, a large number of older adults with comorbid dementia and physical disability depend on family care provided by other older adults. Most Western studies separate caregiving burden and care-related gain as independent analytical dimensions. There is a lack of domestic localized evidence that interprets care experiences under Pearlin's caregiving stress-process model, particularly regarding older-adult informal family caregivers who provide care for older adults in Shanghai. This study aimed to explore the holistic caregiving experiences of this specific group and clarify the internal logical connections between structural antecedents, multiple stressors, buffering resources, and care outcomes, so as to deliver localized empirical evidence for the optimization of long-term care policies and community support services in China.

Methods

Purposive sampling was used to recruit 13 primary older-adult family caregivers aged 60 years and above for semi-structured narrative interviews. Inductive content analysis was performed following Colaizzi's seven-step analytical framework with NVivo 15 software. Four dimensions-credibility, transferability, dependability, and confirmability-were adopted to guarantee study trustworthiness. This study was reported in compliance with the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Results

Five core themes and fifteen corresponding sub-themes were extracted from interview transcripts: (1) Structural caregiving context, including family structural constraints, the influence of filial piety culture, and insufficient aged-care supply; (2) Multiple caregiving stressors, covering primary care burden, independent care decision-making pressure, restricted social engagement, and intra-family conflicts; (3) Limited buffering support resources, involving inadequate formal care services, insufficient informal assistance from relatives, and individual psychological coping strategies; (4) Negative caregiving experiences, including persistent physical exhaustion and sustained emotional depletion; (5) Dual perceptions of caregiving outcomes, consisting of emotional gains from kinship bonding, resistance to institutional care, and long-term anxiety about future care arrangements.

Conclusions

Older-adult family caregivers endure cumulative multi-layered care-related strain, while current formal and informal support resources only produce limited stress-relieving effects. This study extends the

localized explanatory power of Pearlin's caregiving stress-process model within China's older-adult to older-adult family care context. It is recommended to optimize the supply of long-term care insurance services, build community respite care and regular psychological counseling systems, and launch targeted support programs for single-child caregivers to reduce family caregiving burden.

Clinical trial registration

Not applicable

1 Introduction

Global population ageing is accelerating, and the number of older adults living with cognitive impairment combined with physical disability has risen substantially, accompanied by growing demand for informal home-based care^[1]. According to the WHO-issued thematic report on dementia, co-occurrence of dementia and physical dependence creates compound care-giving burdens. As institutional care cannot fully meet such needs, family caregivers constitute the core backbone of the long-term care system^[2]. Epidemiological evidence from China^[3] indicates that low fertility rates and cross-regional mobility of younger generations have weakened intergenerational care-giving capacity. A large proportion of older Chinese adults suffer from concurrent cognitive decline and impaired activities of daily living, rendering family home-based care the dominant care model.

Older-to-older caregivers, defined as informal family caregivers aged ≥ 60 years who provide unpaid home-based care for elderly relatives (including elderly spouses and senior siblings of care-recipients with concurrent dementia and physical disability), represent a prevalent form of community-based home care^[4, 5]. Compared with middle-aged and younger adult child caregivers, older-to-older caregivers are advanced in age, frequently multimorbid, and have limited economic and social resources. Long-term intensive care-giving may trigger a bidirectional vicious cycle of personal ageing and care-related burnout^[6]. Care-recipients with combined dementia and physical disability often exhibit behavioural and psychological symptoms such as agitation, circadian rhythm disturbance, and care resistance, exposing caregivers to persistent physical and mental strain; these caregivers themselves also require physical care and emotional support^[7]. To mitigate home-care burdens, China has piloted the Long-term Care Insurance (LTCI) programme. Nevertheless, current services are constrained by short single home-visit durations and insufficient supply of respite care and psychological support, which cannot fully address the diverse needs of older caregivers^[8]. Existing studies are mostly large-scale quantitative assessments. Qualitative narrative evidence focusing on caregivers for older adults with coexisting dementia and physical disability remains scarce. Most quantitative work measures care-giving burden via scales and fails to capture nuanced, dynamic subjective care-giving experiences^[9, 10]. Synthesised qualitative studies have demonstrated the dual nature of long-term care-giving: it is associated with adverse outcomes, including physical exhaustion, social isolation, financial strain, and self-guilt, alongside positive gains such as deepened kinship and enhanced self-worth. Long-term care-giving also

reshapes household arrangements and induces systemic family changes such as role reversal and transformed communication patterns among relatives^[11].

Evidence from domestic and international studies has identified marked gender disparities in care-giving burden. Women undertake the vast majority of unpaid care work. Influenced by traditional norms of self-sacrifice, they are more vulnerable to anxiety and burnout, and care-related stress intensifies with prolonged care-giving duration^[12, 13]. Existing Chinese studies mainly recruit middle-aged and younger adult child caregivers. Furthermore, available qualitative studies and systematic reviews mostly investigate caregivers of older adults with either dementia or physical frailty in isolation. In-depth narrative enquiries targeting caregivers of older persons with concurrent cognitive and physical impairments are limited, and indigenous qualitative data specific to older-to-older caregiving populations remain insufficient^[14]. The concept of “‘indirect’ illness” proposed by foreign scholars describes secondary physical and mental exhaustion among caregivers resulting from empathy for care-recipients’ suffering. This theoretical perspective has not been adequately explored among Chinese older-to-older caregivers supporting persons with combined dementia and physical disability^[15]. Current research tends to separate care-giving scenarios for cognitive impairment and physical dysfunction, and overlooks unique stressors stemming from the physiological ageing of older caregivers. Immersive qualitative evidence that reconstructs the complete dynamic care-giving trajectory for this double-impairment population is therefore lacking.

2 Materials and Methods

2.1 Aim

This study aimed to explore the complete care-giving experiences of older-to-older family caregivers for older adults with concurrent dementia and physical disability in Shanghai. Based on the care-giving stress process model, it sought to clarify internal logical relationships among structural antecedent contexts, multiple stressors, buffering resources and care-giving outcomes, so as to provide local empirical evidence for optimising long-term care policies and community support services in China.

2.2 Study Design

This qualitative study was designed to understand the real physical and psychological experiences of older-to-older caregivers supporting care-recipients living with concurrent dementia and physical disability. A descriptive phenomenological approach was adopted. Within the phenomenological paradigm, thematic interpretation of meanings represents an interpretation of data, intended to uncover implicit underlying meanings embedded in participants’ lived experiences^[16, 17]. Descriptive phenomenology emphasises that data analysis should be grounded in empirical evidence and participants’ real-life narratives. Interview data were analysed using the seven-step Colaizzi’s phenomenological method^[17]. The analytical procedures were as follows:

Repeatedly read all interview transcripts to familiarise with data and document initial impressions.

Extract significant statements directly related to care-giving experiences of older-to-older caregivers for older adults with concurrent dementia and physical disability.

Formulate formulated meanings derived from these significant statements.

Categorise the formulated meanings to generate preliminary themes and sub-themes.

Integrate themes to construct a comprehensive description of the care-giving phenomenon.

Distill the essential structural description summarising these care-giving experiences.

Return the synthesised descriptions to participants for member checking to refine the findings.

Two researchers independently completed the whole analytical process. Discrepancies were resolved through group discussion to reach consensus on themes, ensuring analytical rigour. This study was reported in accordance with the Consolidated criteria for Reporting Qualitative research (COREQ) checklist.

2.3 Theoretical framework

This study adopted Pearlin's care-giving stress process model as the overall analytical framework^[18]. The model interprets caregivers' physical-mental changes via a sequential pathway: structural antecedent context-stressors-buffering resources-outcomes, which fits well with our objective of exploring the full care-giving trajectory among older-to-older caregivers. Interviews and data analysis were performed following the COREQ reporting guidelines^[19]. Semi-structured narrative interviews were used to collect primary data for in-depth exploration of care-giving experiences.

2.4 Participants and Setting

Purposive sampling was applied to recruit family caregivers of in-hospital older patients from the emergency ward of a tertiary-level hospital in Shanghai. The researcher was affiliated with this hospital and participated in the whole interview procedure. Before each interview, participants were fully informed of study objectives, procedures, and data usage rules. Formal interviews were conducted only after written informed consent was obtained.

Inclusion criteria for caregivers:

- ☑ Aged ≥ 60 years;
- ☑ No cognitive impairment, with clear verbal expression to complete interviews independently;
- ☑ Primary home-based caregiver, providing ≥ 12 hours of care per day for at least 3 consecutive months;
- ☑ Voluntary participation with signed informed consent.

Inclusion criteria for care recipients:

- ☒ Aged ≥ 60 years;
- ☒ Clinical diagnosis of dementia meeting the criteria for major neurocognitive disorder in the Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition, DSM-5)^[20];
- ☒ Physically disabled, assessed as mild disability or worse according to the Trial Assessment Standards for Long-term Care Disability Grading^[21];
- ☒ Presenting comorbid dementia and physical disability.

Exclusion criteria:

- ☒ Hired paid caregivers or non-family carers;
- ☒ Participants suffering from severe physical or psychiatric illness, or extreme emotional instability that prevents effective interview engagement.

The initially planned sample size was 12 participants. Sample size was determined by data saturation using a concurrent strategy of interviewing and coding. After every 2–3 completed interview transcripts, preliminary coding comparison was performed to contrast new textual data against the established coding framework. Recruitment ceased when no new codes or sub-themes emerged across successive interviews, confirmed by collective research-team discussion; the final sample included 13 participants.

2.5 Data collection

Based on a literature review, two pilot interviews were carried out with eligible older-to-older caregivers to test the logic, clarity, and time-cost of the semi-structured interview guide. Drawing on Pearlin's care-giving stress process model and advice from two qualitative nursing researchers, the formal interview guide was revised (Table 1). This study focused on holistic care-giving experiences of older-to-older caregivers for older adults with concurrent dementia and physical disability. Ten open-ended main questions covered four theoretical dimensions: structural antecedents, context, care-giving stressors, buffering resources, and care-giving outcomes. Care-related decision-making dilemmas were not core questions but reserved as optional follow-up probes, activated only when relevant narratives arose during interviews. The guide served only as a reference; question order was flexible, with iterative probing according to participants' responses.

Interviews were scheduled at 15:00 to balance caregivers' daily care tasks and researchers' working schedules, conducted in an independent meeting room adjacent to hospital wards. Each interview lasted 40–60 minutes. Audio-recording commenced after written informed consent. A final open-ended closing question was posed: "Regarding care-giving, is there anything I have not asked that you would like to add?", to capture experiences outside pre-set guide items.

Table 1
Semi-structured Interview Outline Based on the Caregiving Stress-Process Model

Main dimension	Subdimension	Main interview questions
A. Social-structural context	Basic caregiving background	1. How long have you been caring for this older adult? What are your main daily caregiving tasks?
	Individual and family conditions	2. What is your physical health status? Do you have any chronic diseases? How has caregiving changed your family finances and family relationships?
B. Stressors	Objective caregiving burden	3. How has your daily life changed since you started providing care compared with before? How have your personal roles transformed?
B1. Primary stressors	Life and role changes	4. During caregiving, which situations bring you considerable stress, and what are the main manifestations of such stress?
B2. Secondary stress strains		
C. Moderating buffering resources	External social support	5. What kinds of support have you received from family members, neighbours, or community-related services during caregiving?
C1. External resources	Practical effects of support	6. To what extent can such external support relieve your care-related stress? Please share real-life experiences regarding circumstances in which caregiving stress remains unalleviated even with external support.
C2. Intra-personal resources	Intra-personal coping	7. What strategies do you usually use for self-regulation and coping when facing stress from caregiving?
D. Caregiving outcomes	Negative physical- and psychological experiences	8. What physical, psychological, and mental changes have you experienced throughout long-term caregiving?
D1. Negative outcomes	Gains and growth from caregiving	9. Looking back on the whole caregiving journey, which moments or experiences have brought you comfort, rewards, or personal growth?
D2. Positive outcomes	Open-ended supplement	10. Is there anything else you would like to add about your caregiving experience?

2.6 Data analysis

A descriptive phenomenological design and semi-structured narrative interviews were used for data collection. All interview transcripts were analysed strictly following Colaizzi's seven-step phenomenological approach, assisted by NVivo 15 qualitative software for coding and thematic extraction, to synthesise real-world care-giving experiences of older-to-older caregivers for older adults with concurrent dementia and physical disability. The analytical steps were as follows:

- ☒ Researchers repeatedly read full transcripts to grasp participants' care-giving journeys and subjective perceptions, while bracketing pre-existing assumptions to guarantee interpretive objectivity.
- ☒ Screen and extract meaningful original statements closely relevant to the research topic, removing invalid or repetitive content.
- ☒ Abstract semantic meanings from selected statements via open coding to generate discrete meaning units.
- ☒ Merge conceptually similar meaning units and inductively develop sub-themes and core themes to build an initial thematic framework.
- ☒ Explore interrelationships among themes and subthemes, refining the hierarchical thematic model guided by Pearlin's care-giving stress process model.
- ☒ Interpret core phenomena and essential characteristics of older-to-older care-giving experiences based on the final thematic structure.
- ☒ Conduct member checking: return synthesised thematic results and representative quotations to all participants for verification and revision, mitigating researcher interpretive bias.

Dual-independent coding was implemented throughout. Two researchers with qualitative research experience coded transcripts and generated themes separately. Coding disagreements were resolved via collective team discussion. Trustworthiness was assessed across four dimensions: credibility, transferability, dependability, and confirmability, to strengthen the rigour and scientific validity of findings.

2.7 Rigour

Quality control was performed across four established qualitative trustworthiness dimensions: credibility, transferability, dependability, and confirmability.

For credibility: semi-structured narrative interviews, full audio-recording, and verbatim transcription were adopted. Member-checking with participants reduced interpretive bias and ensured findings reflected genuine care-giving experiences.

For transferability: strict inclusion-exclusion criteria were applied. Detailed documentation of the study context, participant characteristics, and full research procedures enables reference for comparable settings and caregiver populations.

For dependability: dual-independent coding and team consensus for disputed codes were used with unified coding rules, supported by NVivo 15 software to achieve analytical stability and reproducibility.

For confirmability: complete audit trails including audio-records, raw transcripts, coding documents, and thematic iteration records were retained. Conclusions were strictly grounded in interview data to minimise subjective researcher interference.

2.8 Ethical considerations

This study complied with the ethical principles of the Declaration of Helsinki, and was approved by the Medical Ethics Committee of the affiliated tertiary hospital (Ethics No. 2025YS-299). Prior to participation, all interviewees received full information about study objectives, interview procedures, data usage, confidentiality rules, and voluntary participation. Participants were informed they could withdraw unconditionally at any time without negative consequences. All participants provided written informed consent.

Strict privacy protection was enforced. All interview data were used solely for academic analysis within this project. Transcripts were fully anonymized with numerical participant identifiers replacing real names; identifiable information, including patient diagnoses and residential addresses, was redacted. Audio files and textual materials were password-protected and stored by designated researchers, accessible only to the research team. Data will be archived according to institutional requirements upon study completion to prevent unauthorised disclosure or misuse.

3 Results

3.1 Sociodemographic findings

Thirteen family caregivers for older adults with concurrent dementia and physical disability were recruited. All caregivers were aged ≥ 60 years and satisfied the inclusion criteria for older-to-older caregivers. Of the 13 caregivers, 8 were female (61.5 %) and 5 were male (38.5 %), with a mean age of 66.5 ± 5.3 years. Caregivers were distributed across three age-group brackets: 60-64 years ($n = 6$, 46.2 %), 65-69 years ($n = 4$, 30.8 %), and 70-75 years ($n = 3$, 23.1 %). Caregiver-recipient relationships included spouses ($n = 6$, 46.2 %), adult children ($n = 5$, 38.5 %), and siblings ($n = 2$, 15.4 %). Daily care-giving hours ranged from 12 to 24 h, averaging 18.2 ± 6.2 h per day. Total care-giving duration varied from 1 to 6 years, with a mean of 2.4 ± 1.9 years. Seven caregivers were retired (53.8 %); nine had senior high-school education or above (69.2 %).

The corresponding 13 care-recipients were older adults living with concurrent dementia and physical disability, with a mean age of 76.9 ± 10.6 years. They fell into the following age-group categories: 60-74 years ($n = 4$, 30.8 %), 75-84 years ($n = 6$, 46.2 %), and ≥ 85 years ($n = 3$, 23.1 %), including 8 females (61.5 %). Levels of physical disability were as follows: complete disability ($n = 7$, 53.8 %), moderate disability ($n = 3$, 23.1 %), mild disability ($n = 2$, 15.4 %), and severe disability ($n = 1$, 7.7 %). All care-recipients had a dementia diagnosis, among whom nine presented behavioural and psychological symptoms of dementia. Socio-demographic characteristics of caregivers and clinical features of care-recipients are summarised in Table 2.

Table 2 Demographic characteristics of participants (*n*=13)

Characteristics	Category	<i>n</i> (%)	Characteristics	Category	<i>n</i> (%)
Family caregiver			Care-recipient		
Gender	Female	8 (61.5)	Gender	Female	8 (61.5)
	Male	5 (38.5)		Male	5 (38.5)
Age group (years)	60-64	6 (46.2)	Age group (years)	60-74	4 (30.8)
	65-69	4 (30.8)		75-84	6 (46.2)
	70-75	3 (23.1)		≥85	3 (23.1)
Daily caregiving hours	12-14 h	5 (38.5)	Disability severity	Mild	2 (15.4)
	24 h	8 (61.5)		Moderate	3 (23.1)
				Severe	1 (7.7)
				Complete disability	7 (53.8)
Total caregiving duration	<2 years	6 (46.2)	Economic status	Good	4 (30.8)
	2-5 years	4 (30.8)		Fair	9 (69.2)
	>5 years	3 (23.1)			
Relationship with care-recipient	Spouse	6 (46.2)	Number of children	0-1	9 (69.2)
	Adult-child	5 (38.5)		2-3	3 (23.1)
	Sibling	2 (15.4)		≥4	1 (7.7)
Employment status	Retired	7 (53.8)			
	Reemployed	1 (7.7)			

	Farmer	1 (7.7)
	Accountant	1 (7.7)
	Freelancer	1 (7.7)
	Other	2 (15.4)
Educational level	Illiterate	1 (7.7)
	Junior college	4 (30.8)
	High-school	5 (38.5)
	Secondary technical school	1 (7.7)
	Bachelor's degree	2 (15.4)

Note: Caregivers refer to older-adult family caregivers aged ≥ 60 years; Care-recipient refers to older adults with comorbid dementia and physical disability. Disability severity was evaluated in accordance with China's Long-term Care Insurance Disability Grading Assessment Standard: Mild disability: partial impairment in activities of daily living; Moderate disability: prominent impairment in activities of daily living; Severe disability: serious impairment in activities of daily living; Complete disability: total loss of activities of daily living.

3.2 Themes

One-on-one in-depth semi-structured interviews were conducted with 13 primary family caregivers of community-dwelling older adults with concurrent dementia and physical disability. Interview recordings were transcribed verbatim and imported into NVivo 15 for analysis. Researchers repeatedly read all transcripts, performed open coding and axial categorization sequentially. Participant recruitment continued until data saturation was achieved. Finally, five core themes and fifteen sub-themes were generated. The overall distribution of coded themes is visualised in Figure 1. Integrating interview findings under Pearlin's care-giving stress process model, a context-specific care-giving stress transmission pathway was constructed (Figure 2). Each sub-theme is described below, supported by selected participant verbatim quotations. The full thematic framework and representative interview quotations are presented in Table 3.

Figure 1 Word cloud illustrating core themes of caregiving experiences among older-adult family caregivers for older adults with comorbid dementia and physical disability

Figure legend. Word cloud generated from qualitative interview coding. Font size corresponds to the frequency of coded themes, reflecting the main lived caregiving experiences of older-adult family caregivers providing care for older adults with comorbid dementia and physical disability

Figure 2 Conceptual framework of caregiving stress transmission based on Pearlin’s caregiving stress process model

Figure legend. This framework adapts Pearlin’s caregiving stress-process model to interpret the caregiving experiences of older-adult family caregivers for older adults with comorbid dementia and physical disability. The structural antecedent context generates primary and secondary stressors. Continuous stress exposure triggers negative caregiving experiences, including physical and emotional exhaustion. These negative experiences are further modulated by limited internal and external buffering resources, and finally form dual positive-negative caregiving outcomes corresponding to the five main themes extracted in this study. Arrows indicate the hypothesized sequential pathway of caregiving-related stress

Table 3 Themes, subthemes, and representative participant quotations

Theme	Sub-theme	Representative quotations
Structural antecedent context	Family-structure constraints (<i>n</i> =4)	"Only-child status increases the caregiving burden." (<i>P</i> 11)
	Influence of filial-piety values (<i>n</i> =5)	"If I do not take care of my own mother, who will?" (<i>P</i> 7)
	Shortcomings of aged-care service supply (<i>n</i> =6)	"Public rehabilitation hospitals cannot meet older people's individual dietary preferences." (<i>P</i> 4)
Multiple caregiving stressors	Primary caregiving burden (<i>n</i> =8)	"He frequently needs care between 12 and 2-3 a.m., waking me up so I cannot sleep for two to three hours." (<i>P</i> 1)
	Care-related decision-making pressure (<i>n</i> =7)	"As the disease progresses, there are inevitably more and more care-related decisions to make." (<i>P</i> 8)
	Restricted social life (<i>n</i> =5)	"I used to enjoy travelling, dancing, and playing cards; now I have none of these things anymore." (<i>P</i> 12)
	Intra-family conflicts (<i>n</i> =3)	"I have quarrels with my wife; this situation is really difficult." (<i>P</i> 6)
Limited buffering support resources	Limitations of formal services (<i>n</i> =7)	"Long-term-care insurance support only comes once every three days for about one hour, mainly for bathing and wiping." (<i>P</i> 9)
	Insufficient assistance from relatives and friends (<i>n</i> =4)	"I seldom share my difficulties with my children. I try to cope by myself, since everyone has their own busy lives." (<i>P</i> 10)
	Individual psychological adjustment (<i>n</i> =6)	"At our age, we can only try to be more open-minded; there is no other way." (<i>P</i> 4)
Negative caregiving experiences	Physical exhaustion (<i>n</i> =7)	"My own health is poor; I suffer from eight or nine different health conditions from head to toe." (<i>P</i> 2)
	Psychological-emotional drain (<i>n</i> =6)	"When I feel upset, I hide somewhere and cry loudly." (<i>P</i> 5)
Dual perceptions of caregiving outcomes	Emotional gains from kinship bond (<i>n</i> =4)	"Thinking about how he treated me well and sacrificed a lot for the family in his younger years, I made up my mind not to abandon him." (<i>P</i> 8)
	Rejection towards institutional care (<i>n</i> =5)	"Sending bedridden older adults with poor eating capacity to nursing homes will not work; they cannot receive adequate care there." (<i>P</i> 3)

Note: n = number of participants who mentioned this sub-theme. Participant represents the de-identified identifier of each interviewee; please fill in the real participant ID extracted from NVivo. These quotations are verbatim excerpts from semi-structured interview transcripts.

3.2.1 Theme 1: Structural antecedent context

The structural antecedent context refers to pre-existing objective circumstances that give rise to subsequent care-giving stress, covering three sub-themes: family-structure constraints, influence of filial piety values, and shortcomings of aged-care service supply.

Some caregivers in this study came from one-child families without siblings to share long-term care responsibilities. There was a lack of alternative caregivers within the household, so one person routinely took full charge of all care tasks. As one participant sighed and stated: "Only-child status increases the caregiving burden." (P11). Deep-rooted local filial piety values created implicit moral constraints; caregivers generally regarded home-based care as an inherent duty for children or spouses and were intrinsically reluctant to place their older relatives in institutional settings. Moreover, standardised care delivered by rehabilitation and aged-care institutions failed to meet older adults' individual dietary and daily-living needs. Many caregivers commented that institutional rehabilitation could not achieve the meticulous care available at home, indicating notable deficiencies in formal aged-care service provision. Additional interview narratives for this theme are presented in Table 3.

3.2.2 Theme 2: Multiple care-giving stressors

Multiple care-giving stressors represent tangible physical and psychological burdens experienced throughout the care trajectory, encompassing four sub-themes: primary care-giving burden, care-related decision-making pressure, restricted social life, and intra-family conflicts.

Round-the-clock care and frequent night-time caregiving generated a substantial physical toll. One participant remarked with exhaustion: "He frequently needs care between 12 and 2-3 a.m., waking me up so I cannot sleep for two to three hours." (P1). Major decisions concerning medical interventions, resuscitation preferences, and institutional placement rested solely on primary caregivers, who bore all associated risks and consequences. The number of care-related trade-offs grew as the participant's disease progressed. Continuous care-giving disrupted leisure activities and social contact, leading to social isolation. Disagreements over care arrangements and role division triggered conflicts between spouses and relatives, and the cumulative effect of multiple stressors further exacerbated care-giving strain.

3.2.3 Theme 3: Limited buffering support resources

Limited buffering support resources denote internal and external resources intended to mitigate care-giving burden, yet with prominent limitations. This theme consists of three sub-themes: limitations of formal services, insufficient assistance from relatives and friends, and individual psychological adjustment.

Home-based services funded by long-term-care insurance and community-based support only provided basic bathing and cleansing with limited frequency and duration, and therefore could not deliver substantial relief. One participant shook their head and observed: “Long-term-care insurance support only comes once every three days for about one hour, mainly for bathing and wiping.” (P9). Professional clinical and nursing guidance was largely hospital-based, with inadequate community-level services. Adult children and relatives could only offer intermittent help due to their own work and family commitments and could not establish sustainable shared-care arrangements. When negative emotions accumulated, few professional psychological counselling resources were accessible, and caregivers had to rely on self-consolation for emotional regulation.

3.2.4 Theme 4: Negative care-giving experiences

Negative care-giving experiences reflect physical and psychological impairment resulting from prolonged exposure to care-giving stress, including two sub-themes: physical exhaustion and psychological-emotional drain.

Uninterrupted care-giving disrupted daily routines and caused fragmented sleep and chronic insufficient rest, aggravating caregivers’ pre-existing chronic illnesses and keeping them in persistent physical fatigue. One participant spoke in a heavy tone: “My own health is poor; I suffer from eight or nine different health conditions from head to toe.” (P2). Psychologically, persistent worry and helplessness were hard to resolve. With few outlets for repressed feelings, some caregivers experienced emotional breakdown and weeping. Combined physical and psychological depletion continuously undermined caregivers’ health status. Further participant accounts are summarised in Table 3.

3.2.5 Theme 5: Dual perceptions of care-giving outcomes

Dual perceptions of care-giving outcomes describe mixed subjective feelings formed throughout the care-giving journey, characterised by positive gains alongside long-term worries. It includes three sub-themes: emotional gains from kinship bonds, rejection of institutional care, and worries about future care prospects.

Close daily companionship strengthened kinship bonds. Past shared memories afforded caregivers inner comfort and psychological strength to persist in care. One participant spoke with emotion: “Thinking about how he treated me well and sacrificed a lot for the family in his younger years, I made up my mind not to abandon him.” (P8), representing one of the few positive gains within care-giving. Nevertheless, most caregivers strongly resisted nursing-home and rehabilitation-facility placement, doubting whether standardised collective care could satisfy older adults’ individualised needs.

Meanwhile, caregivers frequently reported anxiety about the future. They feared that no one would take over care responsibilities once their own health declined, leaving them uncertain about subsequent care prospects. All typical narratives for this theme are compiled in Table 3.

4 Discussion

Using in-depth semi-structured interviews, this qualitative study recruited 13 primary family caregivers of older adults with concurrent dementia and physical disability. Five core themes and fifteen sub-themes were extracted, systematically depicting real-world circumstances of domestic home-based caregivers regarding care-model preferences, care-related decision-making, multi-dimensional physical-mental strains, access to social support resources, and dual positive-negative care-giving experiences. The findings can be systematically interpreted through Pearlin's care-giving stress process model, which divides the complete care-giving trajectory into four core dimensions: antecedent context, stressors, moderating-buffering resources, and care-giving outcomes^[22]. Previous systematic reviews summarising relevant Chinese studies have indicated that most domestic empirical studies adopting this model are cross-sectional quantitative questionnaire surveys exploring variable correlations, while qualitative studies that fully deconstruct care-giving stress pathways based on local interview narratives remain relatively scarce^[12]. Drawing on primary interview narratives, this study constructed a context-specific care-giving stress transmission pathway for local populations, further extending the local explanatory power of Pearlin's model for Chinese family caregivers supporting older adults with concurrent dementia and physical disability. Moreover, this study confirms the dual nature of care-giving experiences, combining burden-related exhaustion and kin-based emotional comfort. It enriches local qualitative evidence on family caregivers within China's ageing context and provides practical references for clinical nursing interventions, community aged-care service development, and optimisation of long-term care insurance policies.

4.1 Preference for home-based care and low recognition of institutional aged-care services

All participants in this study resisted long-term institutional care, arguing that standardised services in rehabilitation and nursing homes failed to meet the personalised dietary and emotional companionship needs of bedridden severely disabled older adults. This finding is consistent with survey results on Chinese middle-aged and older adults' care preferences reported by *Ren et al. (2024)*^[23]. Rooted in traditional filial piety culture, in-home family companionship is regarded as an inherent familial obligation, whereas institutional care is only treated as an emergency alternative rather than a long-term care solution. Existing domestic surveys on disabled older populations mostly adopt quantitative questionnaires to measure caregivers' institutional-care preferences. Such approaches can only reflect macro-level tendencies and cannot concretely reveal inherent contradictions between standardised institutional routines and individualised care requirements of older adults with concurrent dementia and physical disability^[24]. Based on raw narratives from semi-structured interviews, the present study depicts real-world institutional service conditions and interprets deep-seated reasons for caregiver resistance to institutional placement from the perspective of lived experience, compensating for limitations of

quantitative research in exploring subjective inner conflicts. Further practical local constraints were identified from interview data. First, most domestic aged-care and rehabilitation institutions provide homogenised services, lacking customised diets and 24-hour intensive personalised care for long-term bedridden older adults. Second, participants mainly relied on pensions; long-term institutional bed fees and costs for private carers created unaffordable financial burdens. This financial-stress outcome corroborates previous relevant research findings^[25].

4.2 Centralised care-giving decision-making and amplified care-giving stress among only-child caregivers

This study found that major decisions concerning medical treatment, living arrangements, and resuscitation were concentrated on primary caregivers. Only-child participants without sibling support reported markedly heavier psychological distress. This supports the viewpoint of *Zhong et al. (2020)*^[26]: only-child families represent a high-risk group for care-giving burden owing to the absence of peer relatives to share care-giving responsibilities. Prior cross-sectional quantitative studies have confirmed correlations between only-child status and care-giving stress. This qualitative research further uncovered hidden psychological conflicts behind solo decision-making: when adult children offered to quit jobs to share care work, caregivers experienced intense guilt, generating dual psychological strain. Qualitative research on dementia caregivers in Singapore has reported similar family-decision dilemmas; nevertheless, guilt was more prominent among Chinese only-child participants in our sample, stemming from local cultural features of intergenerational attachment^[27]. Additionally, participants described the psychological burden of bearing sole responsibility for risks associated with medical choices such as resuscitation and medication. This mental dilemma is rarely reported in Western multi-sibling-family studies, where joint family discussion of medical plans is common^[28].

4.3 Cumulative triple burden: overlapping financial, physical, and social care-giving strains

Our findings demonstrate that long-term care-giving produces overlapping physical, financial, and social burdens, consistent with results from a large-scale national survey of informal caregivers in Malaysia^[29]. Physically, frequent nighttime supervision caused pervasive fragmented sleep among participants. Combined with years of intensive care labour, participants' pre-existing chronic conditions deteriorated. This aligns closely with the sub-theme of "care-related physical fatigue" described in the LTCI-focused qualitative study by *Liu et al. (2025)*^[8]. Financially, complicated medical-insurance reimbursement procedures available only on workdays created barriers because caregivers could not leave their care recipients to complete formalities. Coupled with limited LTCI subsidy ceilings, household expenditure pressure intensified; such institutional barriers are seldom discussed in international literature. Socially, all participants completely gave up travel, social gatherings, and recreational activities. Friends and relatives gradually distanced themselves due to prolonged serious illness within the household, exacerbating loneliness. This pattern of progressive social isolation corresponds to findings from Western studies on dementia caregivers^[30]. However, structural shortages of alternative care resources in China further aggravate such loneliness. Most existing Chinese studies examine single dimensions of

care-giving burden in isolation. The present study systematically illustrates superimposed effects of these three types of strain and confirms that multiple stressors synergistically amplify caregivers' negative psychological outcomes.

4.4 Insufficient supply and poor accessibility of internal and external support resources

Among available professional support channels, clinical medical and nursing staff represented the most trusted professional group for participating caregivers. Although hired carers, community workers, and LTCI-linked services delivered basic care assistance, service limitations prevented substantial alleviation of multi-faceted long-term care-giving stress. This result agrees with findings from domestic qualitative studies concerning LTCI-supported care-giving^[8]. As China's LTCI scheme and community aged-care service system continue to develop, the capacity of such support resources is expected to improve to better share family care-giving workloads. *Pei et al. (2024)*^[31] pointed out deficiencies in service duration and coverage within current Chinese LTCI, which matches participants' demands for longer home-visit services and higher reimbursement rates in our study. In terms of intrapersonal emotional regulation, most participants relied on self-persuasion to relieve distress and seldom sought formal psychological counselling. Research on Chinese-ethnic caregivers by *Au et al. (2013)*^[32] explains this phenomenon: influenced by traditional cultural norms and stigma, Chinese caregivers are reluctant to seek external psychological support proactively. Standardised caregiver peer-support groups and routine professional psychological counselling are more prevalent within Western aged-care systems. By comparison, constrained by developmental stages of aged-care services and local cultural help-seeking attitudes, China's specialised social-support system for caregivers still requires substantial improvement.

4.5 Dual positive-negative care-giving experiences: kinship bonds as a protective psychological factor

Care-giving experiences in this study were not uniformly negative. While enduring chronic fatigue and irritability, caregivers obtained emotional comfort from spousal and blood-kin ties, generating dual care-giving outcomes. This observation fits dual-outcome assumptions within the stress-and-coping framework. Existing Chinese qualitative studies have likewise demonstrated that exhausting negative perceptions and positive psychological gains may co-exist during care-giving, reflecting the complexity of care-giving experiences^[33]. Many international studies treat care-giving burden and care-giving gain as independent analytical dimensions^[34]. Integrating negative and positive care-giving experiences from primary interview data, our findings suggest that, under East Asian collectivist cultural contexts, family kinship bonds can partly buffer physical-mental exhaustion induced by prolonged care-giving. This adds local empirical evidence regarding positive care-giving experiences among Chinese family caregivers.

5 Implications for clinical nursing, community services, and policy-making

5.1 Systematic training delivered by healthcare professionals

Given participants' heavy physical burden stemming from insufficient home-care skills, healthcare professionals should provide systematic home-care skill training for family caregivers during

hospitalisation and follow-up visits. Training content may include pressure-injury prevention, medication management, and night-time safety monitoring, so as to reduce physical strain caused by non-standard care practices^[35]. Meanwhile, routine screening for anxiety and sleep disturbances should be conducted among caregivers. Those with severe caregiving burnout should be timely referred to psychological support resources.

5.2 Prioritising respite care within community-based services

Participants reported great difficulty accessing short-term respite care. Community aged-care services should prioritise the development of respite-care programmes to meet caregivers' needs for temporary relief while handling personal affairs^[36]. Caregiver peer-support groups can be established to offer emotional outlets and mitigate social isolation. Furthermore, public-facility age-friendly renovation, LTCI application, and medical-insurance reimbursement procedures should be optimised to reduce caregivers' time-related costs.

5.3 Optimising long-term care insurance schemes by policy-makers

Respondents in this study put forward clear practical demands. Policy-makers may optimise LTCI home-visit services, for instance, by appropriately extending single-visit service duration and raising reimbursement levels. It is worthwhile exploring the inclusion of full-day short-term respite care and professional psychological companionship within the LTCI benefit package. Meanwhile, enhanced training for institutional staff, together with customised dietary support and emotional companionship services, may improve caregivers' trust in institutional care.

5.4 Providing psychological and communication support for families

Nurses and community workers can deliver targeted family communication guidance to alleviate feelings of guilt among only-child caregivers. Mediation suggestions should be offered when disagreements emerge over care plans, so as to reduce marital conflicts triggered by care-giving-related disputes.

6 Limitations and future research directions

6.1 Limitations of the study

Purposive sampling was adopted in this study, with only 13 primary home-dwelling family caregivers recruited from a single region. The proportion of older male caregivers in the sample was relatively low, which restricts adequate exploration of gender-based differences within this population. Hence, caution should be exercised when generalising findings to caregivers from other regions and ethnic groups. As cross-sectional interviews were conducted at a single time-point, dynamic changes in care-giving experiences along with disease progression and policy shifts could not be captured. In addition, this study focused exclusively on home-based caregivers, excluding participants receiving institutional care; therefore, comparative perspectives across different care settings are absent.

6.2 Future research directions

Multi-centre mixed-methods studies with enlarged sample sizes are recommended in future work. Standardised care-giving burnout scales can be applied to quantitatively verify the qualitative findings from the present research. Longitudinal follow-up interviews are needed to dynamically examine how disease progression and LTCI policy adjustments shape caregivers' subjective experiences. Intervention programmes targeting only-child family caregivers can be developed based on our results, to test the effectiveness of combined respite-care and psychological-counselling strategies. Further interviews with institutional caregivers should also be supplemented to compare care-giving burden and access to social support between home-based and institutional care contexts.

5 Conclusions

Adopting descriptive phenomenology and guided by Pearlin's care-giving stress process model, this study utilised semi-structured interviews to explore real-world care-giving experiences among 13 older-to-older family caregivers supporting older adults with concurrent dementia and physical disability. Five locally rooted core themes were generated. One-child family structures, constraints imposed by traditional filial piety culture, and deficiencies in formal aged-care services together constituted structural antecedent contexts. Caregivers endured persistent multi-faceted physical, social, and economic stressors from long-term intensive care-giving and sole responsibility for critical care-related decisions. Healthcare professionals represented a key source of support; nevertheless, buffering resources, including community services, LTCI benefits, and psychological counselling, remained insufficient and offered limited relief. Care-giving experiences were dual-faceted: physical and mental exhaustion predominated, yet emotional gains from kinship companionship could partially buffer negative care-giving feelings.

This study adds local empirical evidence for the application of Pearlin's care-giving stress process model among Chinese older-to-older caregivers for older adults with concurrent dementia and physical disability. Targeted countermeasures covering clinical nursing, community services, LTCI policy, and family psychological support are proposed, providing qualitative evidence for improving the long-term care support system and alleviating care-giving burdens among older family caregivers. Multi-centre mixed-methods investigations, longitudinal follow-up, and targeted intervention trials are warranted to further improve the generalizability of the findings.

Declarations

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Data availability

The datasets generated and analysed during the current study are not publicly available due to the potential to identify individual participants, but aggregated anonymised data are available from the

corresponding author on reasonable request.

Ethics approval and consent to participate

This study was conducted in accordance with the principles of the Declaration of Helsinki and was approved by the Medical Ethics Committee of Shanghai East Hospital, China (Approval No. 2025YS-299)

Prior to the interviews, the participants were informed about their anonymity, confidentiality of their information, the research method and objectives, and their right to leave the study at will. All participants provided written informed consent, which was collected and filed prior to each interview.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests

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Figures

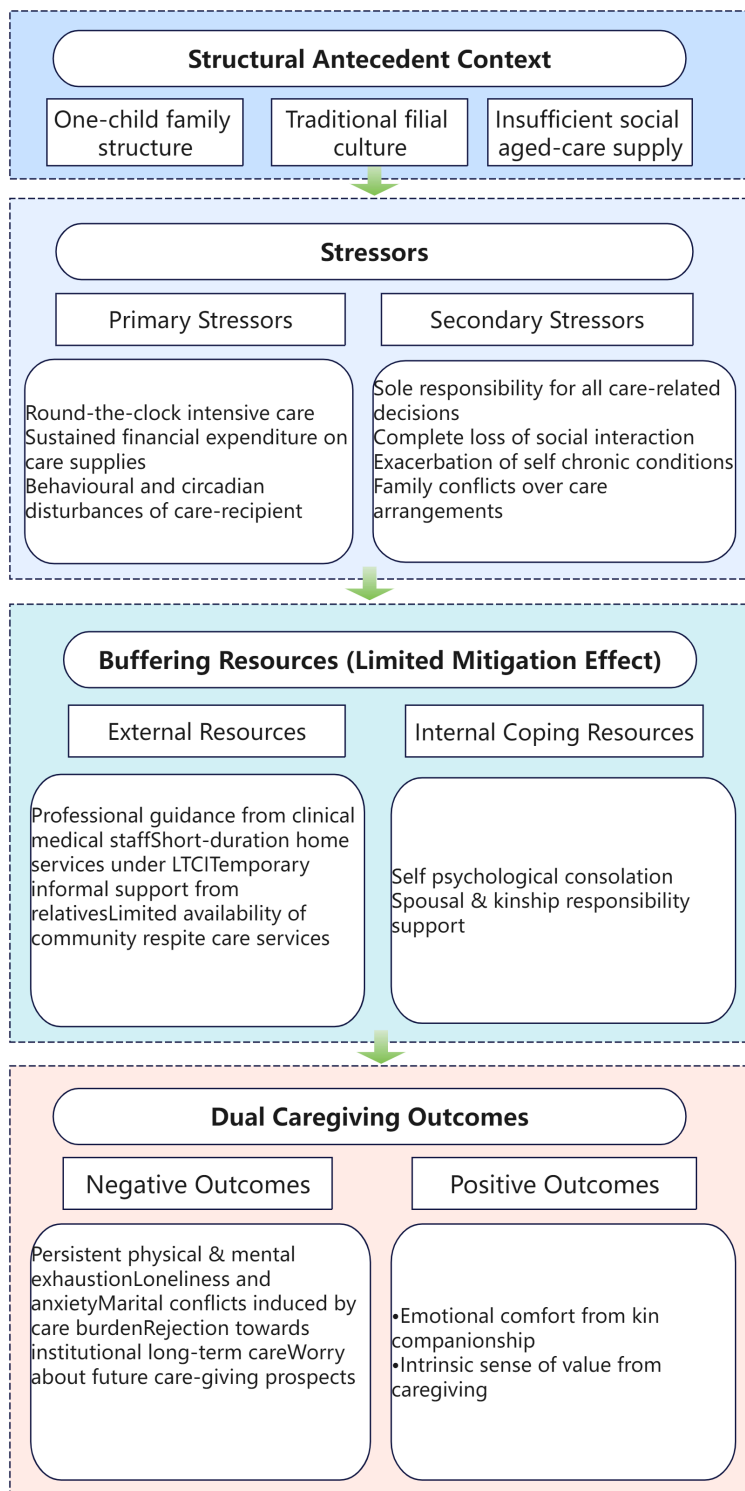


Figure 2

Conceptual framework of caregiving stress transmission based on Pearlin's caregiving stress process model

Figure legend. This framework adapts Pearlin's caregiving stress-process model to interpret the caregiving experiences of older-adult family caregivers for older adults with comorbid dementia and

physical disability. The structural antecedent context generates primary and secondary stressors. Continuous stress exposure triggers negative caregiving experiences, including physical and emotional exhaustion. These negative experiences are further modulated by limited internal and external buffering resources, and finally form dual positive-negative caregiving outcomes corresponding to the five main themes extracted in this study. Arrows indicate the hypothesized sequential pathway of caregiving-related stress

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