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A qualitative study on the subjective experience of prolonged care among family members of patients with moderate to severe dementia

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Abstract

Objectives To explore the family members' subjective experiences of prolonged care for individuals suffering from moderate to severe dementia and to provide evidence supporting the development of support strategies and precise interventions targeting this group.

Methods A purposive sampling method was used to select family members of patients with moderate to severe dementia within the neurology department of a hospital in Chengdu City for face-to-face in-depth interviews. Data were analyzed using the seven-step analysis of data from the Colaizzi phenomenological study.

Results Three main themes were identified in this study: (1) Pressures and burdens faced, (2) Lack of social support, (3) Positive changes. In addition, 11 sub-themes were extracted as the subjective experience of prolonged care among family members of patients with moderate to severe dementia.

Conclusion The subjective feelings of families of patients with moderate to severe dementia about prolonged care are complex and specific. Family members face tremendous pressures, still lack social support, and lack coordinated communication among communities, families, and hospitals. In the future, we should learn from the practical experience of prolonged care in foreign countries, fully integrate with China's national conditions, promote the improvement of the prolonged care system for patients with dementia, accelerate the construction of community-based professional care institutions, gain a deeper understanding of the challenges and needs faced by family members, enhance their experience of care, improve their quality of life, and help the patients and family members to better pass through the stage of moderate-to-severe disease.

Keywords Moderate to severe dementia, Family members, Prolonged care, Qualitative research, Subjective experience

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Background

Dementia is a neurodegenerative disease that occurs in the elderly population and is characterized by memory impairment [1]. Currently, more than 55.2 million people worldwide suffer from dementia, with more than 60% of them living in low and middle-income countries [2]. In both low-income and high-income countries, dementia has been shown to be one of the leading causes of care dependency and disability among older people.

In 2019, the global economic cost of dementia was $1.3 trillion, and the global cost of dementia is projected to reach $2.8 trillion by 2030 [3]. Due to the inadequacy of the old-age insurance system and the lack of institutions specializing in the admission and treatment of dementia patients, family members are currently the main caregivers of dementia patients in China. Due to the decline in self-care ability, patients gradually become unable to adapt to society and require prolonged care from their caregivers, and it is estimated that up to 82 billion hours are spent caring for people with dementia worldwide each year [4]. In particular, patients with moderate to severe dementia experience motor and language impairment and cognitive dysfunction, which ultimately leads to the inability to perform daily activities independently and the loss of self-care skills, including the inability to eat, drink and walk independently, which severely affects the quality of life of patients and their families, and dementia has become the most disabling chronic disease of older people [5].

A qualitative study examined the experiences of Malaysian family caregivers caring for persons with moderate to severe dementia. The study found that in addition to actively managing the challenges of psychological and behavioral symptoms of people with dementia, attention should be paid to the cultural background of informal caregivers [6]. A cross-sectional survey study found that the health care needs of patients with moderate-to-severe dementia living in the community of Porto, Portugal, were related to diet, medication, sleep, fall prevention, communication, and caregiving needs, but the researchers found that despite well-structured home care plans for people with dementia, there were still unmet health needs, including caregivers' emotional and psychological balance [7].

Most studies have focused on symptomatic interventions for patients with moderate-to-severe dementia or caregivers. However, with the large number of people with dementia in China, there is a lack of corresponding evidence to investigate the process of caregiving experiences of caregivers of patients with moderate-to-severe dementia. Therefore, this study used a qualitative research methodology to explore the prolonged care experiences of family members of patients with moderate-to-severe dementia in China, to further understand the needs and challenges of this group, and to provide evidence to support the development of supportive strategies and precise interventions for health care providers in China and globally.

Methods

Design

This descriptive qualitative study used one-on-one semi-structured in-depth interviews to understand the subjective experiences of caregivers of patients with moderate-to-severe dementia with prolonged care in China. To obtain a richer and more saturated data base, this study was conducted in West China Hospital of Sichuan University.

Participants

Using purposive sampling method, we selected family members of patients with moderate-to-severe dementia from three wards of the Department of Neurology and the Memory Clinic of West China Hospital of Sichuan University. Purposive sampling considered factors identified in the literature as influencing prolonged care among family members of patients with moderate to severe dementia. These factors included the relationship between the patient and the carer, the gender of the patient and carer, the age of the carer, the number of years spent caring for patients.

The inclusion criteria were as follows: (1) dementia patients with a diagnosis of dementia confirmed by a clinician according to the World Health Organization's International Classification of Diseases (ICD-10) or the United States Diagnostic and Statistical of Mental Disorders, Fourth Edition (DSM-IV), and rated as moderate (2 points) or severe (3 points) by the Clinical Dementia Rating Scale (CDR) [8]; (2) family members who are relatives of the elderly with dementia, including spouses, children and grandchildren, and who have been continuously primary caregiving tasks for ≥ 3 months (jointly identified by the patient and the caregiver themselves); (3) those who are conscious, can accurately express their inner feelings, and can provide detailed information about the elderly; and (4) those who voluntarily participate in this study. The exclusion criteria were follows: Have a serious physical or mental illness, such as heart failure, cancer, severe liver or kidney disease, depression, schizophrenia, etc. This study was approved by the Ethics Committee of West China Hospital of Sichuan University (Ethics Code: HXSY-EC-20211725) and obtained written consent from each participant.

Data collection

This interview script was developed based on the research aim and focused on the following aspects: experience of prolonged care, attitudes towards prolonged care, and the challenges encountered in caring for patients (see Appendix 1) [9, 10].Two researchers (WYH and LY) received appropriate training before conducting the interviews, which included: the theoretical foundations of qualitative research, design of qualitative research, collection of research subjects, data collection and data analysis, and conducted semi-structured in-depth interview method from January to March 2023 to collect data from 17 interviewees. Before the start of the interviews, the interviewees were introduced to this study in detail, and were clearly consulted on the principles of confidentiality, voluntariness, rules of conversation, audio recording and language use. During the interviews, the interviewees were encouraged to express themselves and ask their own questions, and the researcher made flexible adjustments to the outlines and contents of the interviews according to the specific situation in the field. To avoid forgetting important information, the interviews were organized and transcribed within 24 h after the interviews. According to the principle that qualitative research data collection is based on saturation, the interviews were stopped when new information could no longer be obtained in the process of interview data collection. In our study, after interviewing 17 subjects, no new information was obtained, data saturation was reached. Therefore, the sample size for this qualitative study was 17. Subjects were designated as C1, C2..., C17.

Data analysis

Data were analyzed using the seven-step analysis of Colaizzi's phenomenological research data [11]. First, the first author (WYH) checked the information from the interviews several times to ensure the accuracy of the information and transcription. Then, the interviews were read again with all the authors to introduce the process of the interviews and the profile information of the interviewees to ensure that all the authors understood the interviews. Four authors (WYH, LY, FW, and LXS) were assigned four to five interview transcripts, and after the four researchers carefully read all the interview transcripts, each researcher then parsed the transcripts of her assigned interview in detail, coding for recurring and meaningful ideas. The coding results were then discussed with the remaining three researchers and returned to the interviewees for validation. Finally, the preliminary results were discussed and revised by all researchers in the research team to ensure the authenticity of the findings.

Results

Participant characteristics

A total of 17 caregivers of people with moderate to severe dementia were interviewed in this study. The participants ranged in age from 45 to 78 years, and they had been caring for their patients for an average of 5.6 years. All caregivers living with the patients. the Table 1 presents sociodemographic data about the interviewees.

Table 1 Sociodemographic characteristic of the participants (*n* = 17)

Characteristics	Number	Range
Sex		
-female	13	
-male	4	
Age (mean in years)	61.6	45–78
Relationship with patient		
-Daughter	9	
-Son	2	
-Wife	3	
-Husband	2	
-Daughter-in-law	1	
Number of years they have been caring for the patient	5.6	2–16

Table 2 Overview of qualitative themes

Main themes	Sub-themes
Pressures and burdens faced	• heavy financial burden
	• Psychological burden
	• Impact on quality of family life
	• Caregiver burden
Lack of social support	• Shortage of specialized care services
	•Lack of community services
	• Difficulty in accessing medical care
Positive changes	• Active learning to improve caregiving skills
	• Caregivers actively adjust their mental state
	• Caregivers realize realized self-worth
	• Caregivers begin to seek support from others

Key themes

The duration of the interviews was about 45 min, and the interviews were all conducted in the Neurology Ward Conference Room of West China Hospital of Sichuan University. Three main themes and eleven sub-themes are described relating to the subjective experience of prolonged care among family members of patients with moderate to severe dementia. The main themes are: (1) Pressures and burdens faced; (2) Lack of social support; (3) Positive changes (Table 2).

Theme 1: pressures and burdens faced

Heavy financial burden

Due to the long duration of dementia, which is incurable and requires lifelong medication and constant companionship, the financial burden on family members is heavy [12, 13]. Nine family members mentioned the phenomenon of heavy financial burden during the interviews, which included the cost of nanny expenses, higher standard of daily living, and expensive medication. C15: “We have a nanny at home, 5,000 RMB a month, who is only responsible for taking care of my mother, cooking her meals, not doing the laundry or cleaning, and I still have to go to work every day, my salary is basically enough to maintain a basic living.” C8: “My mother passed away, families with many children are still very good, I’m an only child, and I don’t have children, and I don’t have a pension, I live on his little pension, and it’s a very hard life.” C17: “Often can’t buy imported memantine hydrochloride, domestic always feel that the effect of taking it is not good, but imported is more expensive ah, every month the money to take the medicine is a sum of money, every month, when these drugs can be cheaper would be better.”

Psychological burden

Interviewees said that after their loved ones were diagnosed with dementia, the long process of caring for them brought them too much pressure, and their emotions were often up and down, and they were prone to low self-esteem, resentment and guilt.C1: “It feels as if I can’t even be a family member any more, and even if I stick with it, it seems as if I will be burdened with guilt for the rest of my life, and there are some things that you have to go through before you can know how you feel in your heart. “ C2: “The disease will eventually leave you knowing nothing, nothing at all, you can’t walk, you don’t know how to eat, you don’t know how to urinate or defecate, it all sounds really, really cruel”.C9: “Direct caregivers are really emotionally led at times, and just by looking at the mental, energetic, and physical exertion, it’s basically overload.”

Impact on quality of family life

Due to the specificity of the disease, most of the interviewees stated that caring for a person with dementia is very tedious, and the patient is basically unable to leave the person, and the family members seldom have their own personal time. C5: “I stay with her when I have time, but there is really no way, I have to go to class in the weekdays, and my beloved takes care of her at home, and my beloved can’t get out of the house either.” C6: “There are different opinions about caring for children at home, and we have to hire someone, and it’s not easy to find the right person to hire.” C15: “I haven’t gone out every vacation, and when the nanny goes home after vacation, I’m the only one at home, anxiety.”

Caregiver burden

Moderate and severe dementia patients’ self-care ability and cognitive ability have different degrees of reduction, need the all-round care of family members, which includes the patient’s daily life living and every small and cumbersome details of life [14]. C8: “I have anxiety disorder, and I often forget to take my medication due to taking care of the patient!” C15: “My mom couldn’t walk for six months, and in less than a year she couldn’t eat on her own, she can’t take care of herself at all, it takes us close to an hour to feed her.”

Theme 2: lack of social support

Shortage of specialized care services

Most of the respondents said that they have high expectations for professional care, but the current insufficient number of professional institutions in China has led to differences in expectations for professional care institutions. Some family members are reluctant to institutionalize their relatives with dementia and doubt the quality of care provided by the institutions. C3: “There are caregivers, but the quality of care depends on luck. As far as I know, domestic escorts are not only expensive, but their professional knowledge, uneven.” C13: “Most of the institutions nowadays are not suitable for elderly people with dementia, a familiar environment with familiar relatives is the best for patients.” C14: “I want to hire a carer to do long term service at home because I still have my 90 year old mother, it is not good for the old couple to be separated, my dad can still walk at the moment, it is just that I genuinely can’t hire the right one, the carer is not good for him, and he will talk to me at night.” C16: “The cost of training carers is very high at the moment; human resources are very scarce and it’s simply not possible to do one-to-one care for patients.”

Lack of community services

Many family members greatly expect the community to provide daycare services to alleviate some of the caregiving pressures and hope that professional staff will be able to help and care for patients when needed. C14: “I want to hire a community caregiver to do long-term services at home because I still have my 90-year-old mother, and it is not good for the old couple to be separated, and my dad is currently able to walk, eat on his own, play cards, and practice calligraphy, just cannot hire the right one.” C15: “There are basically no services in the community, and patient like my mom, who has to eat four hours a day, the caregivers simply don’t come to the house.” C16: “In fact, caregivers also work very hard, I read a book about a writer’s experience of working as a caregiver in an AD home for the elderly in the U.S. for the purpose of writing this book, and I also wish that there were daycare centers for AD seniors, so that I could go home and sleep at night.”

Difficulty in accessing medical care

Interviewees said that is very difficult to take dementia patients to the doctor due to the patient’s lack of cooperation, fear of going to the hospital, and the lack of systematic guidance from healthcare professionals in their daily lives. C6: “I also don’t know which hospital to go to see a better ah, for this chronic disease, access to medical care is very difficult.” C11: “Since 2016, due to my partner’s neurodegenerative disease doesn’t cooperate with the hospital’s treatment and didn’t go to the hospital to do the examination, treatment, I usually through the access to relevant information completely home health care.” C15: “I think that if I take her to the hospital to ask the doctor, it must be again a variety of examinations. It is troublesome to take her for all kinds of tests because she cannot cooperate at all.”

Theme 3: positive changes

Active learning to improve caregiving skills

Most of the respondents expected to learn more caregiving skills so that they could provide a more professional caregiving experience for their patients, alleviate patient symptoms, relieve caregiving stress, and improve the quality of life for both patients and caregivers. C2: “I think that developing cognitive geriatric habits early on and maintaining the habits that are already in place are very important for caregiving at a later stage of life.” C4: “In the last half a month, after breakfast I will help her massage her calves, and then do some upper limb exercises, and then find some intellectual toys for her to play, I feel that the effect is very obvious in the last week, and the person is very energetic.” C9: “Before my mom got sick, I didn’t know anything but to learn more, and constantly learning is also important to prevent dementia yet, learning new knowledge and skills can keep your brain active.”

Caregivers actively adjust their mental state

Most of the interviewees went through this process from being helpless and frightened to accepting the reality and gradually adapting to the changes, by constantly adjusting and changing themselves to take care of the person with dementia with a better state of mind. C2: “At the moment, what we are doing is that we can have peace of mind when the elderly person passes away.” C7: “So it is important to live in the moment, let go of the obsession because the degeneration is irreversible, lower expectations, accept the existing behavior and cognitive abilities left by the course of the disease, we are not trying to change them, we are trying to fit in, it’s about quality companionship.” C15: “Everyone’s destiny is different, so just go with it and do your best.”’

Caregivers realize realized self-worth

Respondents, while experiencing varying degrees of stress and facing a strong sense of uncertainty about the future, were also relieved when the patient made some progress or felt that the patient needed them, further defining the value of care. C4: “The goal of the current focus of my care for my mom is to prevent the symptoms before they happen! Trying to keep late symptoms from coming as late as possible.” C5: “Just to have a happy old age for her.” C17: “Her symptoms aren’t that severe, she can still do some things on her own, it’s all because I’m there with her every day and taking care of her, and I’m asking them about their experiences every time, I just want her to be stabilized.”

Caregivers begin to seek support from others

The process of caring for people with dementia cannot be separated from the support of the family, society and government. Effective and reasonable support is the bottom line to help the caregiver to get out of the gloom and face the difficulties [15]. C1: “I sent her to a care home with the nature of a hospital for two months and it was very good. My mom used to have a hard time at home, I had to work, her condition was getting worse, I was mentally exhausted, and it affected my mood at work, if we didn’t go to this kind of rehabilitation hospital, we would all be dragged down by her.” C4: “Now I got my mom to the retirement community, the hardware and software services are very good here, I am responsible for taking care of my mom’s daily life, taking care of my mom here makes it very relaxing as I don’t have to do housework!” C7: “What’s more, with the help of my family, it’s much easier for me too.”

Discussion

Enhancing caregivers’ quality of life and broadening quality of life-related research

The present study, by examining the subjective caregiving experiences of family members of patients with moderate to severe dementia, found that most family members of patients with dementia had greater quality of life problems, mainly in the physical, psychological, and social domains, which is consistent with the findings of Farina et al. [16]. This study found that families with more harmonious family relationships and better quality of life had relatively less stressful caregivers. The study suggests that research on the quality of life of family members of patients with dementia can reduce the stress of caregivers to a certain extent, strengthen the bond between family members, create more communication opportunities among family members, further develop family health awareness, and improve the quality of life of people with dementia [17]. Therefore, research needs to focus more on the quality of life of caregivers of people with moderate-to-severe dementia.

This study found that the occupation of the person with moderate-to-severe dementia also affects the quality of life of the caregiver, especially when the person is a highly knowledgeable person or a family decision maker, the mental behavioral abnormality that occurs in the later stages of the patient's life is often difficult for the caregiver to accept, which affects the caregiver's quality of life; and the quality of life of caregivers who have a job with relatively high social status is higher, which may be associated with a higher economic income [18]. Previous studies have found [19] that caregiver quality of life is significantly associated with caregiver burden, with higher caregiving burden being associated with lower caregiver quality of life. Overall, we should give more attention to family members of patients with dementia, strengthen the guidance of their lives, and communicate regularly; assess the health status and care needs of family members in a timely manner, extend psychological care to family members, help family members to reduce the burden of caregiving, and maintain optimistic and open-mindedness, so as to improve the level of quality of life of family members.

Strengthening economic assistance to alleviate economic stress

In this study, it was found that the economic expenditures of patients with dementia mainly include direct medical costs such as outpatient and hospitalization costs, direct non-medical costs such as employment costs and nutritional care for the patient's daily life, as well as the costs of loss of income from the inability of family members' caregivers to work, and the costs of informal caregiving, which is in line with the results of the study conducted by Anand et al. [20]. In this study, we found that 13 out of 17 respondents cited high financial burden, especially in terms of caregiving burden. Coupled with the implementation of family planning policies in the 20th century, most of the current dementia patients in Chinese society have only one child, and it is difficult for family members to combine work and care for the patient at the same time, which makes the burden of caregiving particularly heavy.

In this study, the researchers found that community health centers play a very important role in the prolonged care of people with dementia, and most of the interviewees indicated that they needed some guidance and help from community health service organizations. Strengthening the construction of the community health service system, as a long-term and low-cost preventive health care service accessible to people with dementia, the continuous improvement of its function is the most feasible and effective to alleviate the economic pressure. In the community, early prevention of disease, screening of high-risk groups, early and proactive response to various risk factors leading to dementia, as well as the provision of appropriate treatment and appropriate care guidance to patients and families with dementia, can achieve the timely detection of people with dementia, and early intervention to alleviate the progression of the disease and reduce the economic burden of dementia [12]. It is also possible to establish community-centered health centers for people with dementia, which can integrate the functions of dementia prevention, treatment, health care, rehabilitation, and caregiving, thereby largely addressing the problems faced by families of people with dementia.

In this study, the families of dementia patients with medical insurance or other supplementary commercial insurance had high quality of life and low financial burden. Strengthen the construction of the medical insurance system, with basic medical insurance as the mainstay, supplemented by other commercial insurance and supplementary medical insurance, and a multilevel medical insurance system that comprehensively covers urban employed and non-employed people, urban and rural people in difficulty and rural people, so as to include dementia patients in the scope of the protection, improve the level of protection, and alleviate their financial burdens [21]. Accelerate the implementation of prolonged care insurance system to provide dementia patients with practical health and life protection. China's prolonged care insurance system is still in the pilot stage, and the progress is not yet satisfactory. We hope that China can introduce a prolonged care insurance system adapted to China's national conditions as soon as possible and implement it as soon as possible, to further expand the target of protection, expand the scope of protection, and improve the protection system.

Popularize health education, guide scientific treatment and advocate scientific lifestyles

This study found that more than half of the 17 respondents' caregivers lacked professional knowledge about caregiving and disease prevention and treatment. They lacked knowledge about health care and mental health of people with moderate-to-severe dementia. Duangjina pointed out [22] that strengthening health education for people with dementia and their family members to draw their attention to dementia and popularizing dementia-related knowledge in multiple ways will enable people to have a deeper understanding of dementia and knowledge related to preventing the onset of the disease, delaying exacerbation, and taking care of people daily. As patients with moderate-to-severe dementia, they need to know the risk factors of the disease in a timely manner, to prevent the disease and slow down its progress through preliminary care, changing the bad lifestyle, and adopting the correct treatment in a timely manner. As family members of patients with moderate-to-severe dementia, health education is even more important. Whether in the early stages of the disease, confusion and anxiety, or in the later stages of the disease, fatigue and helplessness, they need scientific guidance and professional help. Health workers can conduct health education in wards, waiting rooms of outpatient clinics, communities and other places, and the publicity methods are not limited to multimedia, brochures, magazines, posters, etc., to solve the difficulties encountered by family members of patients with dementia in detail.

This study found that the care of people with moderate-to-severe dementia is a long and difficult task, and family members often neglect their own physical and mental health during the caregiving process, which makes it important to adopt appropriate psychological support for family members of patients with dementia. The main psychological support tools include team support, sports training, personal skills training, and comprehensive interventions [23]. The main purpose is to enable such caregivers to produce emotional resonance, realize that they are not alone, but a large group of people coping with dementia, encounter negative emotions can be resolved in a timely manner, and the same can be learned from the experience of others in a timely manner, the reasonable expression of their own emotions, and to cope with dementia more calmly.

Improving the prolonged care system and creating a professional care platform

As a chronic progressive disease, dementia imposes more and more demands on family members as the disease progresses, and the burden on family members becomes heavier and heavier. In this study, we found that the passionate demand for scientific care from families of people with moderate-to-severe dementia is reflected in the active learning of appropriate caregiving skills and the seeking of help from caregiving organizations. However, our study also found that respondents currently have access to very little support coming from community health service organizations, and the model is very homogenous.

Chekani's study showed that, family members' knowledge of dementia patients' care skills and nursing care is still insufficient, and it is difficult for patients to receive scientific and formal home care at home, making the quality of dementia patients' care worrisome [24]. Argimon's study showed that, through the establishment of family wards and the participation of family members, targeted home treatment and related care for patients with dementia can effectively reduce the burden on the family and society and is highly important for improving the quality of life of patients and slowing the progression of the disease [25]. At present, China's research on prolonged care for patients with dementia is still in the exploratory stage, and the care model is relatively limited. Community health service centers with convenient locations and affordable and medical care combinations are the first choice for semi disabled elderly individuals [26], but the imperfect regulatory system and the shortage of community health human resources are also current problems. The shortage of professional caregivers and varying levels of education are important issues plaguing prolonged care for people with dementia in China [27, 28]. In the future, we will increase the training of professionals and social workers to enrich the prolonged care service team and form an integrated prolonged care team. We will further enrich care resources and forms to form home-based and community-based prolonged care services for dementia patients.

Discussion

This study provides insights into the subjective experiences of family members of patients with moderate-to-severe dementia during prolonged care, presents the challenges and pressures faced by this group in China, and distills the three themes of pressures and burdens faced by family members of patients with moderate-to-severe dementia, lack of social support, and positive changes. In the study, we found that family caregivers of people with moderate-to-severe dementia have multiple negative psychological experiences, yet caregivers in China still lack the means to actively seek outward relief. In this study, caregivers strongly expressed their desire for professional care, caregivers, caregiving skills, and caregiving knowledge, and their lack of professional caregiving knowledge prevented them from effectively responding to caregiving problems. Through this study, we found that some of the caregivers and patients rejected the nursing institutions due to the isolation of the environment, and they preferred the nearby community day care institutions, which could satisfy their needs for care, as well as their needs for environment and affection. However, China's community care started late and lagged in development. At present, in addition to a small number of day care centers for dementia patients in individual developed cities, most communities do not have departments specialized in providing services for dementia patients and their families, and the professional level of community medical personnel is relatively low, lacking professional neurology, rehabilitation, nutrition and other multi-faceted care teams, and the development of professional care for dementia patients has been slow.

At present, the system of old-age or prolonged care for dementia patients and the social support system in foreign countries are gradually becoming more and more perfect. Therefore, we should reasonably study and learn from the experience of foreign countries in the area of prolonged care for dementia patients, fully combine with the national conditions of our country, and pay attention to the construction of the system of old-age and prolonged care for dementia patients through the efforts of the government, the society, the hospitals, and the families at four levels. Increase the popularization of the disease among medical personnel to the public, encourage caregivers to acquire relatively specialized care skills, actively develop related care support systems, and reduce the burden and pressure of families of patients with moderate-to-severe dementia. This study provides a reliable evidence base for the development and implementation of various measures with the aim of further developing specific interventions to improve the survival and quality of life of family members of patients with moderate-to-severe dementia.

Limitations

There were also some limitations in this study. First, all 17 interviewees were recruited from a single hospital in southwestern China and may have been limited by a single setting. Second, we were unable to dynamically capture changes in caregivers' subjective experiences over time. Therefore, additional longitudinal studies are needed in the future to comprehensively understand the subjective caregiving experiences of caregivers of people with dementia from different regions at different stages of their lives. Therefore, we recommend including a wider range of caregivers in future studies.

Supplementary Information

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Supplementary Material 1

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Author contributions

All authors contributed to this study. Y.W. and D.C. devised the project, Y.W. write the main conceptual ideas, proof outline, and wrote the manuscript. Y.L. conducted experiments, analyzed experimental results, and assisted in manuscript preparation and editing. W.F. and X.L. contributed to data acquisition and analysis, reviewed literature.Y.P. provided logistical and administrative support.All authors reviewed the manuscript.

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Data availability

The datasets used and analyzed during this study are available from the corresponding author upon request.

Declarations

Ethics approval and consent to participate

The study was approved by Biomedical Research Ethics Committee of West China Hospital of Sichuan University (approval no.2021 – 1725). As outlined in the Declaration of Helsinki (World Medical Association [WMA], 2013), the study followed appropriate ethical standards. Signed informed consent forms were collected from participants before inclusion.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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