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Navigating the Journey of Living with Young-Onset Dementia: Experiences of Spousal Caregivers

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Abstract.

Background: Young-onset dementia (YOD) refers to dementia occurring before the age of 65, with Alzheimer's disease being the most common form, posing distinct challenges for spousal caregivers.

Objective: This study aims to investigate the unique experiences of spousal caregivers of persons with YOD in China, where dementia-specific community care services and primary healthcare professionals are relatively lacking, in order to inform the tailored support services development.

Methods: This qualitative-design study utilized semi-structured interviews with 11 spousal caregivers of persons with YOD dwelling in the community. Traditional content analysis was employed to analyze the interview data.

Results: Limited dementia-specific healthcare professionals and low public awareness made diagnosing and accepting YOD a prolonged and challenging journey. Spousal caregivers faced skepticism when seeking diagnosis, exacerbating their burden and emotional stress. Disparities in healthcare professionals and insufficient collaboration between institutions worsened the situation. YOD significantly impacted family dynamics and led to changes in emotional communication within the family. The stigma surrounding YOD raised concerns among spousal caregivers about their children's future in marriage and career, emphasizing genetic risks.

Conclusions: In settings where dementia-specific community care services and primary healthcare professionals are limited and unevenly distributed, integrating support services at both the primary and community levels is crucial for families dealing with YOD in the community. Additionally, raising public awareness about YOD can foster a more understanding and supportive environment, addressing challenges related to stigma faced by affected families, contributing to increased investment in supporting resources, and encouraging individuals to seek help early on.

Keywords: Alzheimer's disease, caregiving experiences, challenges, spousal caregiver, young-onset dementia,

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INTRODUCTION

Young-onset dementia (YOD) refers to the initial symptoms of cognitive and behavioral decline that appear before the age of 65. The prevalence of YOD has recently been estimated at 119 per 100,000, accounting for approximately 5–7% of all dementia cases.[1–3] The China Alzheimer Report 2022 pointed out that there are 15.07 million people with dementia in China, making it the country with the highest number of individuals afflicted by this condition in the world.[4] Although specific statistics on YOD in China are currently unavailable, the substantial dementia population underscores the importance of recognizing YOD's potential impact on individuals in the country.[2,5]

YOD, unlike late-onset dementia (LOD), presents a wider variety of causes and symptoms, resulting in differing patterns of disease progression and diverse care requirements. This variability makes diagnosing, treating, and caring for YOD more complex.[6,7] Moreover, persons with YOD often maintain robust physical health and have ongoing family and career obligations, as well as broader social networks. Consequently, support services designed for LOD fall short of addressing the unique needs of the persons with YOD.[8,9]

YOD has a profound and far-reaching effect on the entire family due to its impact on individuals at a critical stage of development. Dementia is often perceived as an illness of old age; therefore, families affected by YOD undergo unexpected shifts in family dynamics, prompting a reevaluation and adjustment of roles and responsibilities. Persons with YOD and their spousal caregivers are compelled to exit the workforce prematurely, while dependent children may need to shoulder the responsibility of caring for their parents.[10,11] Services tailored specifically for YOD are notably scarce and generally lack specialization, leading to reluctance or even complete avoidance in their utilization.[12] Most families aim to care for loved ones with YOD at home as long as possible, with spouses typically taking on the role of primary caregiver.[9,13] This responsibility places a significant burden on spouses, as they must juggle caregiving duties with their own work, children, and possibly aging parents.[14–16] Managing these diverse roles poses complex challenges.[17] These challenges lead to profound shifts in their self-identity, increased risk of social isolation, and facing higher levels of distress, stress, depression, and coping difficulties.[6,15,16,18–21] It diminishes the quality of life for spousal caregivers and also affects the well-being of persons with YOD, potentially leading to premature institutionalization.[14,22] Stamou et al. highlight the essential role of community support, including home-based assistance, recreational programs, and psychosocial support, as a crucial safety net for families dealing with YOD. [23]

Recently, there has been a growing body of research dedicated to addressing the unique challenges posed by YOD. Significant progress has been achieved in comprehending the subjective experiences of persons with YOD and their families.[11,13,24] France, Norway, and the Netherlands currently have specific measures to address services for YOD within their national dementia strategies.[25] In 2019, Australia also incorporated YOD into its National Disability Insurance Scheme.[26] However, it is noteworthy that existing research on the experiences related to YOD is primarily conducted in developed countries.[11,24] At present, the experiences of spousal caregivers of persons with YOD from developing countries are scarcely documented.

In developing countries, besides the inherent challenges of YOD, spousal caregivers confront additional difficulties due to the scarcity of both dementia-specific community care services and primary healthcare professionals.[27] These challenges include limited awareness of dementia, underdeveloped care systems, and widespread stigma associated with the condition.[28,29] These factors lead to delayed diagnoses, inadequate treatments, and restricted access to proper care and support.[27,30] Understanding the experiences of spousal caregivers is crucial for enhancing their emotional and physical well-being. Consequently, our aim is to delve into the unique experiences of spousal caregivers in a context with limited dementia-specific community care services and primary healthcare professionals, focusing particularly on YOD. We seek to illuminate their experiences to inform the development of more effective, family-centered support services specifically tailored to the challenges of caring for persons with YOD in resource-limited environments.

METHODS

Study design

This qualitative design study utilized semi-structured interviews to explore the caregiving perspectives and experiences of spousal caregivers of persons with YOD in China. Institutional review

Table 1
Characteristics of spousal caregivers

Code	Gender	Age	Relationship with care-recipient	Education level	Duration of caregiving (y)	Care recipient's age	Care recipient's CDR	Residence
C1	M	62	Husband	University	10	62	3	Urban
C2	M	56	Husband	Junior high school	3	58	3	Rural
C3	M	60	Husband	Senior high school	4	57	3	Rural
C4	F	57	Wife	Senior high school	5	56	3	Urban
C5	M	57	Husband	Junior high school	4	58	1	Rural
C6	F	59	Wife	Primary school	2	58	2	Rural
C7	M	58	Husband	College	4	55	1	Urban
C8	M	59	Husband	Junior high school	6	58	3	Rural
C9	F	46	Wife	College	4	59	2	Urban
C10	F	59	Wife	Senior high school	1	61	2	Urban
C11	M	63	Husband	University	1	63	1	Urban

CDR, Clinical Dementia Rating.

board approval was obtained from the academic institution of the first author. Informed consent was obtained from each participant after the details, limitations, risks, benefits of the study, as well as the option to withdraw at any time, were explained.

Setting and sample

In order to explore the unique challenges associated with younger age in YOD, we employed a purposive sampling strategy to recruit spousal caregivers of persons with YOD (currently under 65 years old), from the memory clinic of a university-affiliated hospital in Shanghai, China between October 2022 to April 2023. Although the memory clinic is located in Shanghai, patients from various provinces across China sought diagnoses there. Data saturation was reached after 11 participants were interviewed. The criteria for data saturation are met when additional interviews fail to uncover new ideas related to the study's purpose.[31] Table 1 provides a summary of each spousal caregiver's characteristics. To safeguard the privacy of spousal caregivers, all the data were de-identified.

During routine follow-up, the staff of the Memory Clinic inquired about the willingness of spousal caregivers of persons with YOD to participate in the study. Upon obtaining consent from interested individuals, their contact information was provided to the researcher. One researcher then contacted these individuals via telephone, introduced the study, and answered their questions about the research, and conducted an initial phone screening to determine their eligibility. Eligible spousal caregivers were those who co-resided with persons with YOD (regardless of the specific dementia type) and served as their primary caregivers in a home-based setting, providing a minimum of 8 hours of care daily. They also needed to be able to communicate freely with the investigators. After obtaining the participants' consent, the researcher established communication with them on WeChat to continue the research process. WeChat is an intelligent instant messaging and social media application widely used in China. It supports features such as voice messages, video calls, as well as the exchange of pictures and text.[32]

Data collection

Given that spousal caregivers are geographically scattered across different provinces, we conducted online Mandarin interviews through WeChat video calls to enhance the inclusivity of our study. According to previous statistical data, as of December 2020, there were 986 million people in China accessing the internet via mobile phones, and the number of internet users aged 50 and above reached 329 million.[33,34] Over 94% of smartphone users actively use WeChat.[35] Therefore, choosing WeChat video calls for interviews enables us to involve spousal caregivers who do not reside in Shanghai, while also addressing the limitations of phone call interviews, which fail to capture non-verbal cues such as facial expressions. We also offered participants the option to meet in person or via telephone if they lack access to video calls, ensuring that no one was excluded due to technological limitations. Prior to initiating data collection, we obtained written informed consent from the research participants through online electronic signatures.

Our interview guide comprised a series of open-ended questions designed to elicit detailed insights into the experiences of spousal caregivers of persons with YOD. These questions included: "(1) Can you describe your loved one's current condition? How did you first realize that your spouse was ill? (2) Please walk us through the process of obtaining the diagnosis. (3) In what ways has your life changed due to your loved one's illness? (4) During your caregiving journey, what are some of the main challenges you have faced, and how have you addressed them? (5) Has your relationship with the people around you been affected by YOD? (6) What kind of help, if any, have you received so far in your caregiving role?"

To further deepen our understanding, we incorporated probes tailored to each participant, focusing on areas such as emotional impact, changes in family dynamics, and the availability and adequacy of support services. These probes were designed to adapt to the flow of the conversation, allowing us to explore the unique experiences and perspectives of each participant in greater depth.

All interviews were conducted via WeChat video calls by a researcher, except for one spousal caregiver who was not proficient in using WeChat video. As a result, this participant underwent a telephone interview. The duration of the interviews ranged from 35 to 126 minutes. All interviews were promptly recorded and transcribed verbatim. To protect the interviewees' privacy, identifying information was removed from the transcribed files. All transcribed texts were uploaded to QSR NVivo 12.0 for qualitative data management, organization, and analysis. The attributes of the spousal caregivers (gender, age, number of years of caregiving) were collected through an online demographic questionnaire. The clinical dementia rate (CDR) score of persons with YOD was assessed by the staff of the Memory Clinic during routine follow-up every six months.

Data analysis

We adopted conventional content analysis approach for data analysis. This method relies on encoding categories directly from textual data, enabling us to conduct exploratory interpretations of the collected rich data.[36] Our full research team consists of 7 individuals with backgrounds in dementia caregiving, clinical diagnosis and treatment of cognitive impairments, epidemiology, community interventions for dementia, gerontology, and global health. Among them, four members, including two nursing graduate students and two faculty members, form the coding team.

We used a two-cycle encoding approach. In the first cycle, Xy. C and J. W independently read each transcript multiple times to familiarize themselves with the data and to annotate content related to the experiences and perspectives of spousal caregivers for persons with YOD. The coding team held weekly meetings to compare and discuss discrepancies in the first cycle coding. Any disagreements were resolved in the full team meeting. The codebook was developed during the analysis of the first five transcripts to reflect the caregiving experiences and perspectives of spousal caregivers for persons with YOD. It was then used to code the remaining transcripts. When new codes emerged, they were discussed among the coding team before being added to the codebook. In the second coding cycle, J. W, Jq. W, and Xy. C. compared and analyzed the codes for patterns, similarities, and differences. Through this comparison, codes that shared commonalities were grouped together to form categories. Next, the categories were refined by analyzing them for underlying connections and relationships. This led to the identification of sub-themes, which captured more specific aspects of the data. This step involved looking for nuanced differences and specific dimensions within each category. Finally, these sub themes were distilled into overarching themes that captured the central ideas and patterns in the data.[37] For example, sub-themes such as the impact of YOD on spousal caregivers' family roles and the maintenance of family integrity were distilled into a theme named 'YOD Alters Family Dynamics and Relationships'. The transition from initial codes to final themes is iterative, requiring continuous comparison and refinement to comprehensively capture the essence of participants' experiences and perceptions. The analysis and coding of data were conducted in Chinese-language environment. Themes, sub-themes, and quotations were translated from Chinese into English by a bilingual researcher, and then back-translated by two master-level students.

In the process of data analysis, we utilized memos to clarify coding decisions. In instances where additional information was needed, we revisited the original quotations. Multiple strategies were employed to establish qualitative rigor.[38] For credibility, we regularly invited community engagement consultants, including social services staff and researchers with expertise in policy development and implementation science, as external consultants to review and challenge our interpretations. To ensure dependability, we conducted regular coding team meetings to discuss the usage of coding and codes, and maintained summaries and memos of all discussions among members to keep track of the interpretations.

RESULTS

Three themes about the unique caregiving experiences of YOD spousal caregivers were identified: (a) the journey of seeking and accepting the diagnosis of YOD; (b)YOD alters family dynamics and relationships; and (c) resources challenges facing spousal caregivers.

The journey of seeking and accepting the diagnosis of YOD

Navigating the maze to obtain accurate diagnosis

Due to busy work commitments and limited knowledge about YOD, some spouses didn't notice the early subtle changes it caused, or most of them simply interpreted these changes as normal signs of aging or menopause, without ever connecting them to dementia. As the changes posed challenges to daily life, spousal caregivers started to proactively seek medical consultation. However, the insufficient availability of dementia-specific healthcare professionals, coupled with the denial of persons with YOD about their condition to maintain self-identity, resulting in a significant delay in obtaining accurate diagnoses. Memory clinics in mainland China are limited, primarily concentrated within major tertiary hospitals situated in major cities, and the number of specialized healthcare professionals is also inadequate. Most spousal caregivers and persons with YOD initially navigated through various levels of hospitals, seeking medical advice from departments such as "Internal Medicine," "Cardiology," and even "Traditional Chinese Medicine". Only one spousal caregiver, a university teacher, initially consulted the memory clinic. Some healthcare professionals lacked knowledge about YOD, leading to inaccurate diagnoses and improper referrals. Consequently, most spousal caregivers shared a similar experience of seeking medical diagnoses for persons with YOD across various departments and hospitals. An interesting finding was that persons with YOD residing in rural or remote areas eventually arrived at the Memory Clinic in Shanghai and received accurate diagnoses, mainly due to their relatives or spouses working in Shanghai, thus reducing information asymmetry.

> "*At first, my husband refused to go to the hospital. He believed that having a good appetite and high sleep quality as before was considered normal. He was still able to communicate effectively, just in unfamiliar places, he seemed unconfident and hesitant to move forward. I took him to consult with numerous hospitals and many doctors. However, most doctors were unaware of the cause, so they would suggest that I seek advice from the next department, and many of these suggestions were not suitable. As a result, we ended up going in circles at the hospital.*" -C4

Some spousal caregivers expressed that throughout their persistent pursuit of medical consultation, they encountered a distinct lack of understanding and support, both from their relatives and healthcare professionals who were unfamiliar with YOD. To their dismay, some medical professionals even mistakenly believed that individuals with mental health issues were spousal caregivers rather than the persons with YOD, deepening the spousal caregivers' sense of helplessness and isolation. As one spousal caregiver said, "*It seemed like everyone around thought he was normal, while I stood alone, insisting that he was sick (crying). Ironically, even some doctors thought I was overly anxious and prescribed anti-anxiety medication for me to take, not for my husband. This has been really difficult for me.*" -C4

Navigating the path to accepting YOD diagnosis

Upon receiving the diagnosis of YOD, almost every spousal caregiver initially responded with doubt, denial, and shock. One spousal caregiver used the expression 'the sky fell' to describe the overwhelming feeling of receiving the diagnosis. The stereotype that dementia is a disease affecting only older adults, combined with the stigma associated with young onset, made it challenging for spousal caregivers to accept the diagnosis of YOD. Most of them actively sought additional consultations with specialized medical professionals to validate the accuracy of the diagnosis. Some spousal caregivers, upon learning that there were others who also "suffered from YOD" and hearing examples of persons with YOD being younger, seemed to generate a sense of identity. This feeling alleviated their sense of shame and anxiety, ultimately improving their acceptance of the YOD diagnosis.

As one spousal caregiver shared, "*Initially, when they informed me about her dementia, it was difficult to accept since she was not that old. However, another* *doctor later clarified that it was YOD and shared examples of persons with YOD younger than my wife. This new perspective helped me better come to terms with the situation.*" -C3

YOD alters family dynamics and relationships

The impact of YOD on spousal caregivers' family and social roles

YOD struck people at a life stage marked by substantial family responsibilities, including caring for aging parents, supporting dependent children, and providing financial support for the family's development. Before YOD onset, clear role divisions and cooperation existed among spouses. However, persons with YOD experienced a gradual weakening of their original roles and responsibilities within the family. To maintain family stability, spousal caregivers underwent a significant shift in their life focus, taking on additional family responsibilities and unforeseen caregiver roles. The once-reciprocal relationship, characterized by mutual support and care, began to erode, giving way to predominantly one-sided caregiving responsibilities. Increasingly caregiving tasks encroached upon the roles that spousal caregiver played in their workplaces, social lives, and other family relationships. YOD affected the employment capabilities of both spouses, thereby impacting the economic security of most families. These unexpected changes disrupted the balance of family dynamics and caused significant emotional and psychological impacts on spousal caregivers.

One caregiver encapsulated this transformation, revealing, "*Previously, my main task was to work outside to earn an income, while all the household chores were taken care of by my wife, and I hardly needed to deal with any household tasks. Now, however, my role has shifted significantly, and I find myself managing nearly all household tasks and responsibilities.*" -C5

One caregiver described the difficulties of maintaining family balance in the context of a person with YOD being unable to fulfill household responsibilities, saying, "*Before my wife fell ill, we shared the household responsibilities together. But now, I need to take care of my sick wife and elderly father, and also tend to the crops. I don't have time to do anything else, nor the opportunity to make friends anymore. I'm most afraid of getting sick myself because my wife can't pick up the slack as she used to. I have to persist in doing these tasks even when I'm unwell, and it's truly agonizing.*" -C8

Another caregiver described the sacrifices made in her profession, "*I used to have a pretty high salary, but in order to take better care of him, I quit my job to spend more time with him. Now, most of our expenses are supported by my parents and siblings.*" -C7

Changes in emotional communication dynamics

As the disease progressed, persons with YOD experienced a gradual decline in their language and cognitive abilities, which was often accompanied by emotional detachment. The vibrant language communication and emotional exchanges that had once characterized their relationships with their spouses dwindled. This situation posed significant challenges for maintaining empathetic connections between persons with YOD and their spousal caregivers. Almost all spousal caregivers found it increasingly difficult to share emotional experiences with persons with YOD and gain emotional support from them. A caregiver expressed this loss, saying, "*He used to be very humorous. When I got upset, he would cheer me up and make me laugh. Now, we hardly communicate, and it seems like we can't establish any connection at all. It saddened me when neighbors treated us unfriendly due to his unusual behavior, but I could only endure the situation alone. I can no longer confide in my husband because he lacks the capacity to understand.*" -C6

Despite the decline in emotional communication with persons with YOD, a remarkable transformation occurred in the emotional connection between spousal caregivers and their children. Most children became more concerned about the well-being of their healthy parents, engaging in more frequent communication and providing emotional support. A caregiver shared this positive development, saying, "*I discuss everything happening at home with my daughter now. She often calls to inquire about my health and acknowledges the contribution I make to family harmony by taking care of my wife.*" -C2

Impacts of genetic risk-associated stigma on children's marriage and career

Some spousal caregivers expressed concerns about the stigma linked to the genetic risk of YOD, fearing its impact on their children's marriage and career development. At the time of the YOD diagnosis, many of these children were in the initial stages of job hunting or preparing for marriage. One participant had advised her son to conceal his father's YOD diagnosis in romantic relationships, attributing his father's symptoms to accidents or other causes.

Another participant, whose child's genetic test result was negative, hoped that her son would openly share the result of his genetic test in romantic relationships to demonstrate that he does not carry the risk of YOD. Some caregivers avoided having their children undergo genetic testing to prevent the psychological distress that positive results may bring.

After diagnosis, some participants hesitated to apply for appropriate disability certification, and this led to a lack of access to necessary national policy support. Spousal caregivers explained that because YOD can be hereditary, it could potentially affect their children's careers. This concern prompted them to avoid documenting the diagnosis to prevent hindering their children's future opportunities.

Maintaining family integrity

Most spousal caregivers recognized that providing proper care to the persons with YOD preserves the integrity of the family, promotes the holistic development of their children, fosters emotional communication among family members, and strengthens familial bonds. This held immense significance for them as they placed great importance on familial relationships and family culture. Some spousal caregivers admitted that maintaining the integrity of the family was their ongoing motivation for providing care to persons with YOD.

> "*When my wife fell ill, I hadn't yet retired, and balancing work and family responsibilities was indeed quite tiring. However, when it comes to maintaining the integrity of our family, I am motivated solely by love, without feeling any pressure. Despite my wife's severe illness and her deteriorating condition, her presence in our home* maintains its wholeness. *I find this aspect crucial, especially for our daughter, as it significantly impacts our communication.*" -C1

Resource challenges facing spousal caregivers

Limited access to dementia-specific healthcare professionals

Due to the shortage of specialized healthcare professionals for dementia, such as dementia-specialized neurologists, psychologists, and nursing staff, most spousal caregivers were confronted with significant daily caregiving challenges. They were unable to receive timely and convenient professional support from the primary healthcare system in their daily care. This resulted in significant anxiety, helplessness, and fear among spousal caregivers, overwhelming them emotionally. One caregiver vividly expressed this emotional struggle, saying, "*Whenever my husband's neuropsychiatric symptoms flare up, such as agitation, I desperately hope to get professional help immediately. However, community healthcare professionals don't understand what dementia is; they can't offer me any useful assistance. Consulting doctors at major hospitals usually involves a waiting process. The waiting process is too agonizing for me, and I feel helpless, not knowing what to do. I'm really anxious, I can't wait.*" -C4

For residents in remote areas, the uneven distribution of dementia-specific healthcare professionals further exacerbated this situation. The lengthy commute introduced many inconveniences for subsequent follow-ups, leading to disruptions in the treatment plans for persons with YOD. One caregiver from a northern city in China said: "*There are no specialized professionals for this illness in our local area, so we have to go to Shanghai for medical consultations. Some neuropsychiatric medications that control the symptoms of dementia can only be obtained at specific hospitals, which is really inconvenient.*" -C7 Another caregiver mentioned, "*Due to the distance, follow-up visits and* obtaining *prescribed medication are too troublesome. I am considering temporarily discontinuing my spouse's medication.*" -C2

Insufficient caregiving support resources

The distinctive onset age of YOD restricted the availability of intergenerational support for spousal caregivers in managing caregiving responsibilities. The support they received from family and friends primarily focused on emotional rather than instrumental assistance. The high demand for social engagement and companionship among persons with YOD increased the demands on spousal caregivers' time and energy, thus exacerbating their burden. Due to limited caregiving support resources, some spousal caregivers, despite dealing with their own health issues, still had to fulfill their responsibilities. While many preferred to provide care at home, partly due to the absence of personalized care services in institutional caregiving settings, they also desired respite services to assist them during challenging periods, such as when dealing with their own health issues. Unfortunately, dementia-specific community care services and primary healthcare professionals do not yet meet the needs of this population, and there are significant regional disparities.

"*He needs to eat multiple times per meal, and I'm concerned that the nursing home may not provide the personalized care he requires. Consequently, I prefer to take care of him myself. Sometimes, I also fall ill, and during those moments, I wish for assistance in caring for him or a place where he can receive short-term care. Unfortunately, such a service doesn't exist. His father is already 86 years old and unable to help me take care of him. There came a point when I couldn't cope alone anymore, so I had his younger sister come over to help me for a while. However, she also has a job, so she can't assist me for an extended period; she can only be a temporary solution.*" -C4

> "*My wife loves going for walks. When neighbors greet her, she responds with joy and often initiates conversations herself. She enjoys the company and care of others. Initially, when I was busy with work, I would ask our daughter to pay more attention to her mother. However, I primarily handle daily matters because our daughter is still in school and also requires parental attention.*" -C1

Another caregiver said, "*There's no help available because my relatives and friends are all busy with their jobs. At most, they call to check on me, which brings me some comfort. In the city, there might be volunteers who come to help, but in the countryside, there are no such services.*" -C3

Limited information support

Although China had done a lot of publicity on dementia, the focus had mainly been on late-onset dementia. All spousal caregivers stated that before receiving a diagnosis of YOD, they had never known that dementia could occur at a younger age. The lack of public awareness of YOD resulted in affected families suffering from discrimination and misunderstanding from the general public. Due to limited access to information about YOD, most spousal caregivers lacked the relevant knowledge and skills for YOD care, including medication treatment, disease progression, and daily life considerations. Furthermore, they also lacked comprehensive information about support policies available to persons with YOD, including details on potential government assistance programs, insurance coverage, and other forms of financial and logistical support. This hindered spouses from effectively adapting to the caregiver role.

One spousal caregiver highlighted their knowledge gap, stating, "*We currently lack knowledge about YOD, such as what we should pay attention to in terms of diet. I don't know. I also don't know where to obtain this knowledge, so I often feel caught off guard.*" -C11 Another caregiver emphasized the need for public awareness, saying, "*There was so little publicity about YOD; people don't understand, and we face discrimination everywhere in our daily lives.*" -C5 Some spousal caregivers, when asked if they are familiar with YOD-related policy information or China's pilot long-term care insurance, said they had not been exposed to such policies and had heard of long-term care insurance for the first time.

DISCUSSION

This study delves into the caregiving experiences of spousal caregivers for persons with YOD in settings where specialized social services and dementia-specific healthcare professionals are scarce. It adds to the relatively sparse body of research on YOD from developing countries, enriching our understanding of the complex and multifaceted caregiving experiences these spouses face. The insights gained from this research illuminate the distinct challenges and dynamics inherent in caring for persons with YOD, significantly advancing our comprehension of the nuances of this challenging condition.

Delayed diagnosis of YOD is a widespread phenomenon, stemming from its diverse etiology and atypical early symptoms, which differ from the typical late-onset presentations.[7,39–41] In developed countries, the average delay ranges from 3.4 to 4.7 years.[40,41] However, in developing countries and regions, the delay is often more severe due to both the inherent difficulty in diagnosing YOD and the lack of dementia-specialized healthcare professionals.[28,42] Our research participants frequently needed to consult multiple departments before receiving an accurate diagnosis at the memory clinic. This situation is further exacerbated in rural and remote areas with limited healthcare professional coverage. Among our study participants, individuals in rural and remote areas ultimately obtained accurate diagnoses mainly because they had connections to areas with ample healthcare professionals, which reduced information disparities. Another universal factor contributing to delayed YOD diagnosis is low awareness,[8,40,41] particularly in developing countries and regions.[27,28,43] This delay occurs in two main ways: firstly, limited public awareness may lead to mistaking YOD symptoms for normal aging, menopause, stress, or other conditions, thus delaying medical consultation initiation.[8,39] Secondly, healthcare providers' lack of professional knowledge often results in incorrect referrals and diagnoses, further prolonging the diagnostic process.[40,44] Delays in diagnosing YOD can impede access to crucial information, support, and services, leading to uncertainty regarding disease prognosis, interpersonal challenges, employment issues, and future planning for persons with YOD and their families, thereby adversely affecting their quality of life.[39,40,45]

Previous research indicated that unconscious biases among healthcare professionals may lead to dismissive attitudes towards individuals seeking consultation.[11,46,47] Our findings suggested that some healthcare professionals dismiss the symptoms presented by persons with YOD, while viewing spousal caregivers who persistently seek diagnosis as overly anxious, particularly when the caregiver is female. This tendency appears to be attributed to the relatively healthy physical state of persons with YOD, while dementia is often associated with older adults. Moreover, there exists a prevalent societal stereotype that women are more susceptible to emotional responses such as anxiety and depression,[47] which may contribute to female caregivers encountering greater obstacles in actively pursuing a diagnosis. Spousal caregivers expressed profound feelings of helplessness and isolation as a result of these suspicions.

Due to the significant impact of YOD on individuals of working age, it presents unique challenges for the entire family, distinct from those of LOD.[15,45,47,48] Persons with YOD often prematurely withdraw from the labor market and their family roles. Spousal caregivers must juggle multiple identity tasks to maintain family balance. In order to provide better care for persons with YOD at home for as long as possible, our research participants frequently chose to sacrifice their own career development, social activities, and hobbies. This may be related to China's traditional collectivist culture,[49–51] where, in contrast to the Western emphasis on individualism, Chinese society prioritizes family collectivism and integrity,[30,50,51] thus opting to sacrifice personal growth and well-being for the overall interests of the family.[49,51] In the Confucian paradigm, both spouses are expected to fulfill predetermined reciprocal caregiving duties and obligations to maintain family harmony.[50,51] However, the family's economic security, the caregiver's self-identity, development and interpersonal relationships are all affected, with spousal caregivers facing a heightened risk of social isolation.[47]

Moreover, the impact of the illness gradually diminished the reciprocal intimate relationship and emotional support between spouses. Consequently, spousal caregivers were left to confront the challenges of the disease alone, bearing a heavy emotional burden and psychological pressure. In contrast to LOD, persons with YOD typically maintain relatively healthier bodies, exhibit diverse caregiving needs, and require more social engagement and involvement in proactive activities.[15,22,47] Consequently, spousal caregivers of persons with YOD shoulder a heavier burden of care and household responsibilities. Our participants expressed profound concerns about the potential impact of YOD on their children's career development and romantic relationships. This concern may be associated with a heightened sense of shame due to the higher genetic susceptibility of YOD compared to LOD.[40] Consequently, individuals often tended to conceal the fact that their parents are affected by YOD, which could hinder them from obtaining appropriate support to some extent.

Despite the significant caregiving burden and psychological pressure experienced by spousal caregivers of persons with YOD,[10,14,20] available support resources are very limited. Chinese caregivers typically rely on familial support structures when facing caregiving challenges.[50] However, the unique early onset of YOD limited spousal caregivers' access to intergenerational and peer-relative support. Globally, there is a scarcity of professional services tailored to address the unique needs of persons with YOD, often lacking in age sensitivity and tailored support.[8,9,12,44] In China, specialized health services specifically targeting YOD are currently non-existent, and research focusing on YOD health services is still in its nascent stages. Furthermore, resources for dementia-related care, including long-term care facilities, community-based services, and dementia-specific home care, are still in the early phases of development. The challenges of inadequate diagnosis and management of dementia persist, particularly in rural and remote areas.[28]

When caring for persons with YOD in developing countries like China, spousal caregivers encounter several primary challenges. These encompass a scarcity of dementia specialists, mainly concentrated in first-tier cities, which makes accessing professional support difficult; an underdeveloped care system with inadequate dementia-specific services, particularly in primary care settings, and significant regional and urban-rural disparities; and caregivers lacking the necessary knowledge and skills required to adequately care for persons with dementia, with limited avenues to acquire such knowledge and skills.

Enhancing the knowledge training of medical professionals in developing countries to improve their understanding of YOD,[39] along with establishing multidisciplinary diagnostic and treatment teams and specialized YOD services, can streamline the medical consultation process, significantly shorten diagnosis time, and alleviate the caregiving burden.[40] Strengthening cooperation between regions (such as resource-rich major cities and remote rural areas) and across different levels of hospitals (such as general practitioners in primary care institutions and specialists in tertiary care institutions) is also crucial for the timely diagnosis and post-diagnostic support of YOD.[52,53] This cooperation can lower the referral threshold for persons with YOD, thereby shortening the path to obtaining professional support. Additionally, high-level multidisciplinary memory clinics can provide professional training to lower-tier healthcare institutions, enhancing the primary healthcare system's ability to offer specialized YOD support. Cross-regional cooperation may mitigate the uneven distribution of dementia specialists in developing countries. The emergence of telemedicine can eliminate time and geographical barriers, improving the efficiency of professional services. This facilitates cooperation between regions and across different levels of hospitals, offering a promising solution to enhance the limited and unevenly distributed dementia support and services in developing countries.[54–56]

Previous studies showed that increasing the understanding and awareness of YOD among primary care professionals, especially nurses, can benefit affected individuals and their families.[48] Our study participants often expressed a preference for caring for persons with YOD at home. Community dementia care specialists can provide YOD family caregivers guidance on caregiving knowledge and skills, and develop practical, personalized care plans for affected families.[7,57] Our findings suggested that spousal caregivers could receive peer support and a sense of identity from others facing similar situations, which could alleviate psychological stress. Community care specialists can act as facilitators for peer support within the region, helping to establish a peer support network for spousal caregivers in similar circumstances.

YOD profoundly affects every family member,[45] highlighting the need for family-centered, diverse, and flexible interventions to better meet the varying needs of different families. In addition to offering professional and daily life support, interventions should incorporate culturally sensitive psychosocial support to address the emotional and psychological stress experienced by family members.[15] It is imperative to provide genetic counseling to children affected by YOD to mitigate the stigma associated with genetic factors. Moreover, interventions must dynamically adapt to changes in the condition and living situations, covering the entire course of the disease, including palliative care and end-of-life care. Previous research demonstrated that uncertainty about the prognosis of dementia serves as a barrier for family caregivers in preparing for death.[58,59] Although discussing death at a relatively young age is generally considered taboo, especially in Chinese culture, timely discussions about palliative care and end-of-life care following a clear diagnosis are necessary and beneficial.

Current research has also highlighted that spousal caregivers encounter misunderstanding and discrimination regarding YOD from various sources, including healthcare professionals, throughout their caregiving journey. Most caregivers perceived a lack of public knowledge about dementia. Therefore, public education about dementia should be a priority for governments in developing countries.[49] Enhancing public awareness and understanding of YOD can help eliminate stigma, discrimination, prejudice, and isolation. This can promote early diagnosis and interventions, providing a more supportive and understanding environment for affected families.

In this study, all spousal caregivers were recruited from a single large memory clinic. While this clinic does receive patients from across the country, it is important to take into consideration that individuals without access to specialized dementia-specific health professionals were not included in the current study. However, qualitative research is not aimed at capturing every individual's experience. The richness and depth of qualitative data allow us to explore complex issues and gain a nuanced understanding of the spousal caregivers' experiences and perceptions. As we did not conduct long-term follow-up with the study participants, the research findings may not reflect changes in caregiving experiences over time and as the condition progresses. Additionally, as there is a scarcity of specific information regarding the types of YOD, the findings do not ascertain whether distinct types of dementia lead to divergent caregiving experiences among spousal caregivers.

Conclusion

This study explored the experiences of spousal caregivers of persons with YOD in a context with limited dementia-specific primary healthcare professionals and social services. YOD affects every family member. The lack of public awareness about YOD, including among some healthcare professionals, coupled with limited dementia-specific primary care services, poses significant challenges for spousal caregivers. They face substantial care burdens and psychological stress with minimal support services available. To reduce diagnostic delays and care burdens, it is necessary to enhance healthcare professionals' understanding of YOD, provide specialist YOD services, and foster collaboration among regions and hospitals at different levels. Telehealth can help overcome limited professional resources, uneven distribution, and geographical and time constraints. Raising public awareness about YOD is crucial for promoting early diagnosis and interventions, reducing stigma and discrimination, and fostering a supportive and understanding environment for those affected by YOD. Currently, research on YOD in developing countries is scarce, and further studies are necessary to comprehensively understand this unique population in the global context.

AUTHOR CONTRIBUTIONS

Xiaoyan Cui (Data curation; Formal analysis; Investigation; Project administration; Writing – original draft); Junqiao Wang (Conceptualization; Formal analysis; Methodology; Supervision; Writing – review & editing); Xueting Tang (Data curation; Validation); Ding Ding (Funding acquisition; Resources; Supervision; Writing – review & editing); Bei Wu (Supervision; Validation; Writing – review & editing); Qianhua Zhao (Resources; Supervision; Writing – review & editing); Jing Wang (Conceptualization; Formal analysis; Funding acquisition; Methodology; Project administration; Writing – review & editing).

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CONFLICT OF INTEREST

The authors have no conflict of interest to report.

DATA AVAILABILITY

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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