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Navigating young-onset dementia caregiving: A qualitative study of unmet needs, support, and resilience

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Abstract

Aim

To explore the unmet needs, support experiences, and resilience strategies of informal caregivers of persons with young-onset dementia (YOD) in Singapore.

Background

YOD is defined by symptom onset before 65 years of age and presents caregiving challenges distinct from later-onset dementia. Despite these distinct challenges, evidence on the experiences and support needs of young-onset dementia caregivers in Singapore remains limited.

Design:

A descriptive qualitative study.

Methods

Semi-structured interviews were conducted with 11 informal caregivers of persons with YOD recruited through a neurocognitive service in Singapore between October and December 2024. Data were analysed using reflexive thematic analysis.

Results

Caregivers described YOD caregiving as emotionally and physically demanding, socially isolating, and financially disruptive. Their experiences were shaped by limited access to age-appropriate services, poor visibility of resources, and stigma surrounding dementia in younger persons. While caregivers drew on resilience strategies including self-care, meaning-making, humour, faith, and support from family, peers, and community networks, these efforts were insufficient. Overall, the findings highlight a mismatch between the complex realities of YOD caregiving and the services currently available to support caregivers.

Conclusion

Although caregivers demonstrated resilience and adaptive coping, YOD caregiving in Singapore remained constrained by limited access to visible, tailored, and age-appropriate support. More coordinated support is needed to address caregivers' life-stage, psychosocial, and practical needs.

Impact:

This study extends understanding of YOD caregiving in an underexamined Asian context and highlights the need for healthcare and community services that better address caregivers' needs. The findings can inform the development of more responsive models of caregiver support and future intervention research.

Patient of Public Contribution:

This study did not include patient or public involvement in its design, conduct, or reporting.

Introduction and Background

Dementia is a progressive neurodegenerative condition that affects cognition, behaviour, functional ability, and social participation, with substantial consequences for both persons living with dementia and their informal caregivers (World Health Organization [WHO], 2023). While dementia is commonly associated with older age, young-onset dementia (YOD) refers to dementia with symptom onset before the age of 65 and represents a clinically and socially distinct subgroup (Hartmann et al., 2021). Compared with later-onset dementia, YOD is more heterogeneous in aetiology and may present with behavioural, executive, language, or mood-related symptoms rather than memory impairment alone, contributing to delayed recognition and diagnostic uncertainty for families (Carcaillon-Bentata et al., 2021; Mendez, 2006; Popok et al., 2022).

For informal caregivers, the demands of YOD extend well beyond practical care tasks. Existing research shows that caregivers of persons with YOD frequently experience heightened emotional distress, physical exhaustion, social isolation, financial strain, and disruption to work and family roles (Bannon et al., 2022; Bayly et al., 2021; Flynn & Mulcahy, 2013; Lew et al., 2025; Lim et al., 2018; Walter & Pinquart, 2020). Unlike caregiving in later-life dementia, YOD caregiving is often experienced as a developmentally "off-time" event, as families encounter progressive cognitive decline during what is usually regarded as a productive and socially engaged phase of life. Spousal caregivers may experience major changes in relationship identity, while siblings and other family members may need to renegotiate responsibilities in response to the changing needs of the person with dementia (Aslett et al., 2019; Larochette et al., 2020; Pang & Lee, 2019).

In addition, many existing dementia services remain largely oriented towards older adults, leaving younger persons with dementia and their caregivers with limited access to age-appropriate care pathways, meaningful activities, and tailored support resources (Bannon et al., 2022; Blake & Hopper, 2021; Millenaar et al., 2018). Prior studies have also shown that caregivers often struggle with poor visibility of services, unmet psychosocial needs, and insufficient practical guidance across the disease trajectory (Boots et al., 2015; Johannessen et al., 2016; Millenaar et al., 2018). Although caregivers may draw on various coping and resilience strategies such as self-care, humour, faith, peer support, and adaptive coping strategies to sustain themselves, these efforts do not remove the structural and institutional gaps that shape their caregiving burden (Flynn & Mulcahy, 2013; García-Toro et al., 2020; Pang & Lee, 2019).

These issues are especially important in Singapore, where dementia prevalence is rising and caregiving continues to be strongly shaped by family responsibility and reliance on informal care. In Singapore, approximately 28,000 people aged 60 years and above are living with dementia, and local work has

highlighted the economic burden associated with YOD as well as the high burden experienced by its caregivers (Agency for Integrated Care [AIC], 2024; Kandiah et al., 2016; Lim et al., 2018). However, despite growing recognition that YOD differs meaningfully from later-onset dementia, research focused specifically on the experiences of YOD caregivers in Singapore remains limited. Much of the wider dementia caregiving literature continues to focus on later-onset dementia, which may not adequately capture the distinct life-stage, relational, financial, and service-navigation challenges associated with YOD caregiving.

A clearer understanding of caregivers' unmet needs, support experiences, and resilience strategies is therefore important for informing more responsive and age-appropriate support. Qualitative inquiry is particularly valuable in this area because it can illuminate how caregiving burden is experienced, interpreted, and managed within everyday family, social, and institutional contexts. Rather than assuming that the needs of YOD caregivers mirror those of caregivers of older persons with dementia, there is a need to examine how caregiving burden is experienced, interpreted, and managed within everyday family, social, and institutional contexts. Understanding how caregivers describe their challenges, navigate available support, and sustain their caregiving role can provide insights for developing more tailored and contextually responsive support in Singapore.

Aim of the Study

This aim of this study was to explore how informal caregivers of persons with young-onset dementia in Singapore experience unmet needs, access and perceive support, and sustain resilience in the caregiving role.

Research Questions

1. What unmet needs do informal caregivers of persons with YOD experience in Singapore?
2. What forms of formal and informal support do they perceive as available, helpful, or lacking?
3. What strategies do they use to sustain resilience while navigating the demands of young-onset dementia caregiving?

Methods

Study design

This study employed a descriptive qualitative design to explore the unmet needs, support experiences, and resilience strategies of informal caregivers of persons with YOD in Singapore. A descriptive qualitative methodology was chosen to generate a rich, practice-relevant account of caregivers' experiences in everyday language, without moving into highly abstract theorisation (Sandelowski, 2000). This approach suited the present study's focus, on the understanding of how caregiving challenges and support needs are experienced and managed in everyday contexts. Reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007).

Setting and participants

A purposive sampling strategy was used to recruit informal caregivers who were able to provide relevant, information-rich accounts of caring for a person with YOD (Speziale & Carpenter, 2007). Eligible participants were informal caregivers of persons diagnosed with YOD. Caregivers of persons with later-onset dementia or mild cognitive impairment diagnosed after the age of 65 years were excluded. In addition, caregivers who were unable to communicate in English were excluded because interviews were conducted in English.

A total of 37 caregivers were approached. Of these, 24 declined participation and two were unable to proceed due to last-minute emergencies and could not be rescheduled. Eleven informal caregivers participated in the study. Recruitment ceased when the research team judged that sufficient depth and pattern clarity had been achieved in the dataset and no substantively new insights were emerging. One additional interview was conducted after this point to confirm analytic sufficiency.

Research reflexivity

Data collection and analysis were led by an undergraduate nursing student, supported by two registered nurses, as well as an associate professor who is also a Neuroscience Advanced Practice Nurse, with clinical expertise in neuroscience nursing. Given the researchers' professional backgrounds and prior interest in dementia caregiving, reflexivity was maintained throughout the study to critically examine how clinical knowledge, prior assumptions, and disciplinary perspectives might shape data generation and interpretation. Reflexive notes were kept during the research process, and analytic discussions within the team were used to question emerging interpretations and challenge assumptions.

Data collection

Data was collected between October and December 2024 through semi-structured interviews. An interview guide was developed to ensure consistency across interviews while allowing flexibility for participants to describe their caregiving experiences in their own terms (Appendix A). The guide focused on caregiving challenges, support experiences, and coping or resilience strategies, and was refined through internal pilot testing within the research team to assess clarity, relevance and flow. Minor refinements were made to improve question wording and reduce ambiguity before formal data collection.

Each participant took part in one interview, conducted either face-to-face or remotely via Zoom, depending on participant preference and convenience. Interviews were audio-recorded, and for Zoom interviews, audio and video recording functions were used. Field notes were made during and after interviews to capture contextual observations and early analytic reflections. Interviews lasted between 25 and 74 minutes. Basic demographic information, including age and ethnicity, was collected using an electronic form. All recordings and transcripts were de-identified and assigned unique study codes to protect confidentiality.

Ethical considerations

Ethical approval

for the study was obtained from the SingHealth Centralised Institutional Review Board. A waiver for written consent was granted, and verbal informed consent was obtained from all participants prior to interview commencement. Participants were informed about the purpose of the study, the voluntary nature of participation, confidentiality protections, and their right to withdraw at any time without consequence.

Data analysis

Interviews were transcribed verbatim and checked against the audio recordings for accuracy. Data were analysed using reflexive thematic analysis, following the approach outlined by Braun and Clarke (2006, 2021). Reflexive thematic analysis was selected because it offers a flexible yet rigorous approach for identifying patterned meaning across participants' accounts while acknowledging the active interpretive role of the researchers.

Analysis began with repeated reading of transcripts and field notes to support familiarisation with the dataset. Initial codes were then generated inductively from the data, with attention to both explicit descriptions and underlying meanings relevant to caregivers' unmet needs, support experiences, and resilience strategies. Codes were reviewed iteratively across transcripts and gradually developed into candidate themes that captured shared patterns across participants' accounts. Themes were then refined through ongoing comparison with the coded extracts and the dataset as a whole to ensure coherence, distinction, and relevance to the research aims.

Analytic discussions among members of the research team were used to strengthen reflexive engagement with the data, explore alternative interpretations, and enhance analytic depth. Final themes were developed with the aim of producing a credible and meaningful interpretation of caregivers' experiences.

Methodological rigour

Rigour was supported through several strategies. First, the use of semi-structured interviews enabled in-depth exploration of participants' experiences while maintaining focus on the study aims. Second, reflexive memoing and field notes supported transparency in the analytic process. Third, regular team discussions encouraged critical reflection on assumptions and interpretations during coding and theme development. Finally, an audit trail of interview, transcription, coding, and analytic decisions was maintained to support methodological transparency and dependability (Lincoln & Guba, 1985). This study approached rigour through reflexivity, analytic transparency, and close engagement with participants' accounts, which is consistent with contemporary expectations for qualitative research using reflexive thematic analysis (Braun & Clarke, 2021).

Findings

Participant characteristics

Eleven informal caregivers of persons with YOD participated in the study. Participants included spouses, siblings, and one friend, with caregiving duration ranging from one to four years. Most were female, and caregiving was undertaken across varied employment and income circumstances, highlighting the diverse yet substantial life-stage demands associated with YOD caregiving (Table 1**)**.

Table 1
Characteristics of informal caregiver participants (n = 11)

Participant	Current age	Patient age at diagnosis	Caregiving years	Gender	Ethnicity	Relationship	Employment status
P1	60	57	3	F	Chinese	Sibling	Unemployed
P2	65	62	2	M	Chinese	Spouse	Unemployed
P3	62	64	3	F	Eurasian	Spouse	Employed, full-time
P4	56	56	2	F	Chinese	Spouse	Unemployed
P5	63	62	2	M	Chinese	Spouse	Employed, part-time
P6	64	63	2	M	Chinese	Spouse	Unemployed
P7	64	64	2	F	Chinese	Spouse	Employed, part-time
P8	49	52	1	F	Chinese	Friend	Employed, full-time
P9	60	56	3	F	Indian	Sibling	Employed, part-time
P10	67	64	2	M	Indian	Spouse	Unemployed
P11	60	63	4	F	Chinese	Spouse	Employed, full-time

Note. Mean caregiver age = 61 years (SD = 4.97); mean age of caregiver at diagnosis = 59 years (SD = 4.47); mean age of person with YOD at diagnosis = 60 years (SD = 4.22); mean caregiving duration = 2.3 years (SD = 0.79). F = female; M = male.

Overview of themes

Analysis generated four interrelated themes that captured how caregivers experienced YOD caregiving in Singapore: (1) Living with cumulative and disruptive caregiving demands; (2) Navigating a misaligned and hard-to-access support system; (3) Sustaining caregiving through adaptation and resilience; and (4) Seeking recognition, connection, and tailored support **(**Table 2**).**

Table 2
Themes and subthemes

Themes	Subthemes
Living with cumulative and disruptive caregiving demands	Psychosocial and physical burden
	Social withdrawal and relational disruption
	Financial insecurity and employment strain
Navigating a misaligned and hard-to-access support system	Age-incongruent dementia services
	Poor visibility and fragmented access to support
	Reluctance to engage formal caregiving services
Sustaining caregiving through adaptation and resilience	Restorative self-care practices
	Meaning-making through gratitude, humour, and faith
	Acceptance, role adjustment, and adaptive coping
Seeking recognition, connection, and tailored support	Relational support from family, peers, and community
	Need for psychological, financial, and activity-based support
	Education, advocacy, and stigma reduction

Together, these themes suggest that YOD caregiving was experienced not simply as an emotionally demanding role, but as a form of caregiving shaped by cumulative burden, age-incongruent services, and the ongoing need for adaptation within insufficiently responsive systems.

1. Living with cumulative and disruptive caregiving demands

Psychosocial and physical burden

Caregivers described YOD caregiving as a deeply disruptive experience that affected emotional well-being, physical health, social relationships, and financial security. These burdens were rarely experienced in isolation; rather, caregivers spoke of strain as cumulative, with one challenge often intensifying another. Emotional distress was common, particularly when caregivers witnessed the progressive decline of a loved one while also trying to manage employment, family commitments, and daily responsibilities.

Many participants described frustration, helplessness, sadness, and guilt in response to changes in the person with dementia and the increasing demands of caregiving. For some, the caregiving role gradually displaced their own personal interests and sense of self.

“I get exasperated… I shout… after that, I feel regret… I don’t understand what’s going on in her head… A lot of things I wanted to do when I retired... that’s not really happening.” (P10)

Social withdrawal and relational disruption

Social disconnection further compounded this burden. Several caregivers described withdrawal from social networks, abandonment by friends, or increasing loneliness after the diagnosis, particularly when others did not understand behavioural or personality changes associated with YOD. For spousal caregivers, the transition from partner to caregiver also created a sense of relational loss and emotional isolation.

"... a lot of our close friends… have not contacted us ...So that's very sad ... since her condition, they don't dare to ask us out." (P6)

Financial insecurity and employment strain

Financial strain was another major dimension of disruption. Caregivers described difficulty balancing paid work with caregiving responsibilities, and some reduced working hours or left employment altogether. Even among those with relatively higher incomes, the cost of paid caregiving services was viewed as burdensome, contributing to uncertainty about the sustainability of long-term care.

“Financial issues always exist… money is never enough… Without a steady income, we’re eating into our savings.” (P4)

2. Navigating a misaligned and hard-to-access support system

Beyond the direct demands of caregiving, participants described the additional burden of navigating support systems that were perceived as poorly aligned with the needs of younger persons with dementia and their caregivers. These challenges were not only related to the availability of services, but to how services were structured, accessed, and experienced in practice.

Age-incongruent dementia services

Caregivers often found age-inappropriate care environments discouraging or distressing. Daycare services, when available, were frequently described as unsuitable because they grouped younger persons with much older individuals at different stages of disease progression.

“There are very few daycare facilities for dementia… If you’re in the early stages and still aware, it’s horrible.” (P9)

Poor visibility and fragmented access to support

Participants also described practical barriers to engaging with available services, including poor visibility of resources, fragmented pathways, bureaucratic complexity, and uncertainty about what support existed.

“There’s a lack of visibility around the support systems that are out there.” (P1)

Reluctance to engage formal caregiving services

Some caregivers were aware that services were available but remained reluctant to use them, particularly when they lacked trust in the quality or appropriateness of care. This hesitation further limited the effective use of available support.

“I don’t trust it… as a husband, how can I trust other people to take care of her?” (P6)

This theme shows that caregiver burden was intensified not only by a lack of support, but by the experience of having to navigate a support landscape perceived as fragmented, age-incongruent, and difficult to access.

3. Sustaining caregiving through adaptation and resilience

Restorative self-care practices

Despite these pressures, caregivers described a range of strategies that helped them sustain themselves in the caregiving role. Resilience did not mean the absence of distress; rather, it reflected ongoing efforts to adapt emotionally, cognitively, and practically to the evolving realities of YOD caregiving. Participants described drawing on self-care practices such as reading, exercise, music, walking, and spending time alone. These activities provided brief moments of relief, reflection, and emotional recalibration.

"My exercise time is my meditation time. I exercise and go for long walks, and then think through and rationalise things. " (P9)

Meaning-making through gratitude, humour, and faith

Caregivers also described internal coping processes, including practising gratitude, using humour, accepting change, and consciously reframing the caregiving role. Others described willingness, duty, or faith as important sources of strength. These strategies appeared to function as ways of making sense of difficult circumstances, enabling caregivers to sustain their engagement despite ongoing challenges.

“I practice gratitude, no matter how bad things are… It’s about changing your mindset and not letting things get you down” (P9)

"I like to make light of situations… sometimes I laugh, make a joke… without being offended." (P10)

Acceptance, role adjustment, and adaptive coping

For some, adaptation involved recognising that the person they knew had changed and learning to respond to a “new person.”

“We have to adapt to this new person.” (P8)

Taken together, these accounts suggest that resilience was not a stable individual trait, but an ongoing process of adjustment that enabled caregivers to move on despite persistent emotional and practical challenges.

4. Seeking recognition, connection, and tailored support

Relational support from family, peers, and community

Although caregivers drew on personal coping strategies, they consistently emphasised that resilience alone was insufficient. Sustaining caregiving required recognition, understanding, and support from family, peers, communities, and services. Participants described both the value and the unevenness of such support.

Family support was often a key source of reassurance and shared responsibility, but caregivers also described tension when caregiving roles were unevenly distributed. Peer connections, community groups, and faith-based networks provided emotional validation and a sense of being understood by others facing similar experiences.

“I felt supported by family, as they talk to me and tell me to take care of myself, because they understand that caregivers are under-recognised. And I’m thankful for that.” (P10)

“In my family, other siblings can go about their life as usual, knowing that there is one person who can take care of this. However, sometimes it can be very difficult, when there is finger-pointing and pushing of responsibilities, resulting in conflicts… ” (P9)

Need for psychological, financial, and activity-based support

At the same time, participants expressed a strong need for better psychological support, more visible and affordable services, meaningful activities for persons with YOD, and greater public understanding of dementia in younger persons.

"We go to a young-onset social club with other patients and caregivers. Sometimes, we just text other care partners, just to talk to someone who understands." (P4)

" ...it's easy for me to confide in them, because they have walked through the road, and I'm looking at some of their stories, ... to draw strength from them." (P11)

Education, advocacy, and stigma reduction

Several highlighted the importance of caregiver education, clearer guidance, and public advocacy to reduce stigma and improve readiness for caregiving.

"There's no dedicated space for YOD, so my dream is to have a place run by young-onset patients, a safe space where they have purpose. People could visit for coffee, learn about dementia, and create both employment and advocacy opportunities." (P3)

"I needed to learn more about dementia, so I attended a talk on its types and coping strategies. Now I remember to keep him occupied with activities to slow progression." (P7)

This theme underscores that caregivers were not simply asking for more support in a general sense, but for support that was visible, age-appropriate, relationally sensitive, and responsive to the realities of YOD caregiving.

Discussion

This study shows that caregiving for persons with YOD in Singapore is experienced as a cumulative and disruptive form of burden, shaped not only by the emotional and practical demands of care, but also by age-incongruent services, limited visibility of support, and the ongoing need to adapt within insufficiently responsive systems. Although caregivers demonstrated resilience through a range of self-directed and relational coping strategies, these efforts were not sufficient to offset broader structural and institutional gaps. These findings deepen understanding of YOD caregiving by showing how burden is shaped by the intersection of life-stage disruption, service misalignment, and uneven formal and informal support.

The findings may be usefully interpreted through the Stress Process Model (Pearlin et al., 1990), which conceptualises caregiver distress as arising from the interaction between primary stressors, secondary strains, and mediating resources. In this study, primary stressors included the direct demands of supporting a person with YOD, such as emotional strain, behavioural and relational changes, and the progressive disruption of daily life. These were compounded by secondary strains, including work disruption, financial insecurity, social withdrawal, and the difficulty of navigating fragmented or age-incongruent support systems. At the same time, caregivers drew on mediating resources such as self-care, meaning-making, family support, peer connection, faith, and community engagement. Viewed through this lens, the findings suggest that resilience in YOD caregiving does not arise solely from individual caregiver strength, but from the extent to which caregivers are supported in managing cumulative stress. Importantly, the present findings extend this model by highlighting how structural and system-level factors, such as service misalignment and poor visibility of support, function as secondary strains that are embedded within the caregiving context, rather than external to it.

YOD caregiving as cumulative and life-disruptive burden

Caregivers in this study experienced YOD caregiving as emotionally, socially, and financially disruptive, with these pressures often accumulating rather than occurring separately. Participants described emotional exhaustion, frustration, guilt, social withdrawal, relational loss, and financial insecurity, suggesting that

caregiver burden in YOD is not limited to care tasks alone but is embedded in broader disruptions to identity, relationships, employment, and everyday life. This is consistent with previous YOD literature showing that caregivers of younger persons with dementia often report substantial burden, high emotional strain, and reduced quality of life, particularly because caregiving occurs during a life stage still associated with employment, family responsibility, and future planning (Bannon et al., 2022; Bayly et al., 2021; Flynn & Mulcahy, 2013; Lew et al., 2025; Lim et al., 2018).

Unlike later-onset dementia caregiving, YOD caregiving is often experienced as developmentally "off-time," with families confronting progressive decline during what would usually be regarded as a socially and economically active stage of life. This was especially evident among spousal caregivers, who described a profound shift from intimate partner to full-time caregiver. Similar relational and identity transitions have been reported in prior studies, where caregivers described grief, altered reciprocity, and the gradual loss of the person as previously known (Aslett et al., 2019; Larochette et al., 2020; Pang & Lee, 2019). In the present study, these relational disruptions were further intensified by the cumulative nature of caregiving demands, with emotional strain often compounded by social disconnection and economic pressure. Taken together, these findings suggest that the burden of YOD caregiving is multidimensional and intersecting, rather than a series of isolated difficulties.

Support systems were often misaligned and difficult to access

A second key finding was that caregivers often had to navigate support systems that were perceived as poorly aligned with the realities of YOD caregiving. Participants described dementia services as largely designed for older adults, with limited availability of age-appropriate activities, daycare options, and psychosocial support for younger persons and their families. This reflects a persistent mismatch between service design and the life-stage needs of persons with YOD. These findings reinforce earlier research showing that YOD caregivers commonly face poor service fit, limited access to tailored supports, and frustration with care environments that do not reflect the needs or identities of younger persons with dementia (Bannon et al., 2022; Blake & Hopper, 2021; Millenaar et al., 2018).

Importantly, the issue was not only the absence of support, but the experience of navigating a support landscape that was fragmented, insufficiently visible, and difficult to trust. Caregivers described limited awareness of available resources, uncertainty about where to seek appropriate services, and hesitation in using formal support when it was perceived as unsuitable or unreliable. These findings suggest that the organisation and accessibility of services can themselves generate additional burden, rather than simply alleviating it. While previous studies have similarly reported poor visibility of services, unclear care pathways, and unmet informational and psychosocial needs among YOD caregivers, particularly early in the caregiving trajectory (Boots et al., 2015; Johannessen et al., 2016; Millenaar et al., 2018), the present findings extend this work by highlighting how navigating these systems becomes an ongoing and effortful component of caregiving. From the perspective of the Stress Process Model, these structural barriers can be understood as secondary strains that amplify caregiving burden by placing additional navigational and decision-making demands on caregivers.

Within the Singapore context, this finding is especially salient. Caregiving is often assumed to be anchored within the family, yet the present data suggest that family willingness alone cannot compensate for services that are poorly matched to younger-onset dementia. The need, therefore, is not simply for more services, but for support systems that are more visible, age-appropriate, and easier to navigate, and that recognise the distinctive life-stage challenges faced by YOD caregivers and persons living with YOD.

Resilience was adaptive, relational and ongoing

The study also showed that caregivers sustained themselves through a range of adaptive strategies, including self-care, humour, gratitude, faith, acceptance, and role adjustment. These findings echo previous work suggesting that YOD caregivers often rely on meaning-making, personal coping strategies, and adaptive reframing to preserve emotional balance and reduce distress (Flynn & Mulcahy, 2013; García-Toro et al., 2020; Pang & Lee, 2019). However, an important contribution of the present study is that resilience did not appear as a stable personal trait. Rather, it emerged as an ongoing and effortful process of adjustment.

Caregivers did not describe themselves as unaffected by stress. Instead, they described continually recalibrating their expectations, routines, emotions, and identities in response to the changing condition of the person with YOD. In this sense, resilience functioned as a mediating resource within the caregiving stress process, operating through self-care, meaning-making, faith, relational support, and adaptive role adjustment. This interpretation is important because it suggests that resilience should not be romanticised as an individual strength that compensates for limited support. Rather, it should be understood as a dynamic process that may help caregivers endure burden, but does not remove the need for external support and system responsiveness.

This has practical implications. Interventions aimed at supporting YOD caregivers should not focus only on reducing distress, but also on strengthening adaptive coping capacity in ways that are realistic, relational, and responsive to different stages of caregiving. Psychological support, peer connection, respite, and caregiver education may all contribute to resilience, but they must be embedded within a broader context of service accessibility and recognition.

Caregivers sought recognition, connection, and tailored support

Caregivers consistently sought support that was available, responsive, relationally meaningful, and tailored to the lived realities of YOD caregiving. Participants valued family support, peer networks, faith communities, and community groups because these offered understanding, emotional validation, and shared experience. At the same time, they identified continuing gaps in psychological support, practical guidance, activity-based programmes, caregiver education, and public awareness. These findings are consistent with literature showing that social connectedness, peer support, and caregiver education are important components of sustainable caregiving, although they are often unevenly available and insufficiently tailored in YOD contexts (Gerritzen et al., 2023; Grunberg et al., 2022; Johannessen et al., 2016).

A notable feature of the current findings is that caregivers were not only asking for practical help, but also for greater public recognition of YOD as a distinct and often misunderstood condition. This was evident in

their concerns about stigma, limited awareness, and the tendency for public understanding of dementia to remain centred on older adults. Previous studies have similarly shown that misconceptions about dementia, particularly when it occurs in younger persons, can contribute to social withdrawal, delayed support-seeking, and reduced service engagement (Herrmann et al., 2018; O'Connor et al., 2018; Pang & Lee, 2019). In the present study, the desire for advocacy and education appeared closely linked to the desire for more humane and socially responsive caregiving environments. This suggests that tailored YOD support should include not only caregiver-focused interventions, but also broader awareness-building efforts that reduce stigma and improve recognition across healthcare and community settings.

Practice-oriented mapping of support priorities

Based on the findings, a practice-oriented mapping of support priorities was developed to illustrate how caregivers' unmet needs, coping strategies, and desired support responses may be understood together (Fig. 1). Caregivers described substantial emotional, financial, and structural challenges, while also drawing on self-care, emotional adaptation, and meaning-making to sustain themselves in the caregiving role. However, these individual efforts were insufficient without broader external support. The mapping therefore identifies five priority domains: comprehensive and holistic support, access to institutional support and resources, resilient peer and community networks, empowerment and advocacy, and resources, skills, and education. Rather than representing a formal theoretical framework, this mapping serves as a practice-oriented synthesis of the findings and underscores the need for visible, age-appropriate, and coordinated support systems for caregivers of persons with YOD in Singapore.

Implications for practice and service development

Taken together, the findings indicate that YOD caregiving in Singapore requires a more tailored and coordinated support response. Healthcare and community services need to recognise that caregivers of persons with YOD face distinct challenges related to employment disruption, relational role change, financial strain, and age-inappropriate services. Improving the visibility and navigability of support pathways is critical. It may include clearer referral mechanisms, caregiver information resources, and more proactive guidance following diagnosis to reduce the burden associated with navigating fragmented systems. Importantly, support provision should extend beyond the person with dementia to include structured psychological, social, and educational support for caregivers themselves.Age-appropriate activity-based programmes, peer support groups, counselling options, respite pathways, and caregiver education may be particularly valuable in this population. In addition, services should be designed in ways that acknowledge caregivers' life-stage realities, including employment and family responsibilities. Interventions that reduce secondary strains while strengthening caregivers' mediating resources may be especially important in supporting more sustainable YOD caregiving. These implications are highly relevant in Singapore, where informal caregivers remain central to dementia care provision. Thus, strengthening coordinated, visible, and age-appropriate support YOD-responsive pathways may help reduce cumulative caregiver burden and support more sustainable caregiving over time.

Strengths and limitations

This study provides qualitative insight into the experiences of informal caregivers of persons with YOD in Singapore, an area that remains underexplored in both local and wider Asian literature. By focusing on unmet needs, support experiences, and resilience strategies, the study offers a more contextualised understanding of how caregiving burden is negotiated within family, social, and institutional environments. The use of in-depth interviews enabled participants to describe caregiving in their own words, generating practice-relevant insights into both burden and adaptation.

Several limitations should also be acknowledged. The sample was relatively small and drawn from a single neurocognitive service, which may limit transferability of findings to caregivers in other settings,while providing in-depth insight into experiences within a specialist service context. Participants were English-speaking caregivers already connected to formal healthcare services, and their experiences may differ from those of caregivers who are less engaged with services or who come from other linguistic and cultural backgrounds in Singapore, and may face additional barriers to access. This may mean that the challenges associated with service navigation and unmet needs are, if anything, underestimated in the present study. The relatively high number of non-participants also raises the possibility of self-selection bias, with the sample perhaps reflecting caregivers who were more available or more willing to discuss their experiences. Finally, most participants were spouses or siblings, meaning that the perspectives of younger family caregivers, including adult children, remain underrepresented. As caregiving roles and experiences may differ across these groups, caution is needed in extending the findings to all caregiver populations. These limitations suggest the need for future research using more diverse and inclusive sampling strategies.Future research should examine how support needs and resilience processes vary across different caregiver groups and stages of YOD, particularly among underrepresented populations, such as non-English-speaking caregivers and those outside specialist service settings. Intervention-focused research would be particularly valuable in testing how tailored psychoeducational, peer, respite, and navigation supports may improve caregiver outcomes. Future studies should also examine how healthcare and community systems can better coordinate age-appropriate services for persons with YOD and their families.

Conclusion

This study shows that caregiving for persons with YOD in Singapore is shaped by cumulative emotional, social, financial, and structural demands that extend far beyond the direct tasks of care. Although caregivers demonstrated resilience through adaptation, meaning-making, and relational support, these efforts were insufficient to compensate for the limited visibility, accessibility, and age-appropriateness of existing support systems. By highlighting caregivers' unmet needs, support experiences, and resilience strategies, this study underscores the need for more coordinated, tailored, and relationally responsive services for families living with YOD. Recognising these distinct caregiving realities is essential to building a more inclusive and humane dementia care landscape in Singapore.

Abbreviations

YOD
Young-Onset Dementia

Declarations

Ethics approval statement

All research related activities were approved by the SingHealth Centralised Institutional Review Board (CIRB Ref: 2017-2602).

Consent for Publication

Written informed consent was obtained from all participants for the interview.

Confidentiality and anonymity assured in reporting.

Study conducted according to COREQ guidelines for qualitative research.

Participants were recruited through the Neurocognitive Database study at the National Neuroscience Institute (NNI), Singapore.

Availability of Data and Materials

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Conflict-of-interest Disclosure

The authors have no conflict of interest to declare.

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Authors' Contributions

Sim Jia Ying Shamin: Conceptualisation, Methodology, Data curation, Formal analysis, Writing – original draft, Writing – review & editing.

Choong Han Peng Benedict: Data analysis, review & editing.

Ng Su Lyn Adeline: Review & editing.

Tan Yi Zhen Nicole Isabella: Data curation.

Wang Shiyu: Review & editing.

Wentao Zhou: Conceptualization, Methodology, Supervision, Formal analysis, Writing – review & editing.

All authors approved the final manuscript and agree to be accountable for all aspects of the work.

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References

1. Agency for Integrated Care. (2024). *All about dementia*. https://www.aic.sg/caregiving/all-about-dementia/
2. Aslett HJ, Huws JC, Woods RT, Kelly-Rhind J. This is killing me inside: The impact of having a parent with young-onset dementia. Dementia. 2019;18(3):1089–107. https://doi.org/10.1177/1471301217702977.
3. Bannon S, Reichman M, Popok P, Wagner J, Gates M, Uppal S, LeFeber L, Wong B, Dickerson BC, Vranceanu A-M. In it together: A qualitative meta-synthesis of common and unique psychosocial stressors and adaptive coping strategies of persons with young-onset dementia and their caregivers. Gerontologist. 2022;62(2):e123–39. https://doi.org/10.1093/geront/gnaa169.
4. Bayly M, O'Connell ME, Kortzman A, Peacock S, Morgan DG, Kirk A. Family carers' narratives of the financial consequences of young onset dementia. Dementia. 2021;20(8):2708–24. https://doi.org/10.1177/14713012211009341.
5. Blake C, Hopper L. A qualitative investigation into family carers' experiences of living with/caring for a person with young-onset dementia. Int J Care Caring. 2021;5(3):469–87. https://doi.org/10.1332/239788221X16166022097035.
6. Boots LMM, Wolfs CAG, Verhey FRJ, Kempen GIJM, De Vugt ME. Qualitative study on needs and wishes of early-stage dementia caregivers: The paradox between needing and accepting help. Int Psychogeriatr. 2015;27(6):927–36. https://doi.org/10.1017/S1041610214002804.
7. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Res Psychol. 2006;3(2):77–101. https://doi.org/10.1191/1478088706qp063oa.
8. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qualitative Res Psychol. 2021;18(3):328–52. https://doi.org/10.1080/14780887.2020.1769238.
9. Carcaillon-Bentata L, Quintin C, Boussac-Zarebska M, Elbaz A. Prevalence and incidence of young onset dementia and associations with comorbidities: A study of data from the French national health data system. PLoS Med. 2021;18(9). https://doi.org/10.1371/journal.pmed.1003801. Article e1003801.
10. Flynn R, Mulcahy H. Early-onset dementia: The impact on family care-givers. Br J Community Nurs. 2013;18(12):598–606. https://doi.org/10.12968/bjcn.2013.18.12.598.
11. García-Toro M, Sánchez-Gómez MC, Zapata M, L., Lopera FJ. In the flesh: Narratives of family caregivers at risk of early-onset familial Alzheimer's disease. Dementia. 2020;19(5):1474–91. https://doi.org/10.1177/1471301218801501.
12. Gerritzen EV, McDermott O, Orrell M. Online peer support: Views and experiences of people with young onset dementia (YOD). Aging Ment Health. 2023;27(12):2386–94. https://doi.org/10.1080/13607863.2023.2205833.
13. Grunberg VA, Bannon SM, Reichman M, Popok PJ, Vranceanu A-M. Psychosocial treatment preferences of persons living with young-onset dementia and their partners. Dementia. 2022;21(1):41–60. https://doi.org/10.1177/14713012211027007.

14. Hartmann J, Roßmeier C, Riedl L, Dorn B, Fischer J, Slawik T, Fleischhaker M, Hartmann F, Egert-Schwender S, Kehl V, Haller B, Schneider-Schelte H, Dinkel A, Jox RJ, Diehl-Schmid J. Quality of life in advanced dementia with late onset, young onset, and very young onset. J Alzheimer's Disease. 2021;80(1):283–97. https://doi.org/10.3233/JAD-201302.
15. Herrmann LK, Welter E, Leverenz J, Lerner AJ, Udelson N, Kanetsky C, Sajatovic M. A systematic review of dementia-related stigma research: Can we move the stigma dial? Am J Geriatric Psychiatry. 2018;26(3):316–31. https://doi.org/10.1016/j.jagp.2017.09.006.
16. Johannessen A, Engedal K, Thorsen K. Family carers of people with young-onset dementia: Their experiences with the supporter service. Geriatrics. 2016;1(4). Article 28. https://doi.org/10.3390/geriatrics1040028.
17. Kandiah N, Wang V, Lin X, Nyu MM, Lim L, Ng A, Hameed S, Wee HL. Cost related to dementia in the young and the impact of etiological subtype on cost. J Alzheimer's Disease. 2016;49(2):277–85. https://doi.org/10.3233/JAD-150471.
18. Larochette C, Wawrziczny E, Papo D, Pasquier F, Antoine P. An acceptance, role transition, and couple dynamics-based program for caregivers: A qualitative study of the experience of spouses of persons with young-onset dementia. Dementia. 2020;19(8):2714–31. https://doi.org/10.1177/1471301219854643.
19. Lew ZH, Ng ASL, Zhou W. Young onset dementia informal caregiver experience in caregiving: A systematic review. J Adv Nurs. 2025;81(10):6333–46. https://doi.org/10.1111/jan.16811.
20. Lim L, Zhang A, Lim L, Choong T-M, Silva E, Ng A, Kandiah N, Grill J. High caregiver burden in young onset dementia: What factors need attention? J Alzheimer's Disease. 2018;61(2):537–43. https://doi.org/10.3233/JAD-170409.
21. Lincoln YS, Guba EG. Naturalistic inquiry. Sage; 1985.
22. Mendez MF. The accurate diagnosis of early-onset dementia. Int J Psychiatry Med. 2006;36(4):401–12. https://doi.org/10.2190/Q6J4-R143-P630-KW41.
23. Millenaar JK, Bakker C, van Vliet D, Koopmans RTCM, Kurz A, Verhey FRJ, de Vugt ME. Exploring perspectives of young onset dementia caregivers with high versus low unmet needs. Int J Geriatr Psychiatry. 2018;33(2):340–7. https://doi.org/10.1002/gps.4749.
24. O'Connor D, Mann J, Wiersma E. Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. J Aging Stud. 2018;44:45–51. https://doi.org/10.1016/j.jaging.2018.01.010.
25. Pang RC, Lee DTF. Finding positives in caregiving: The unique experiences of Chinese spousal caregivers of persons with young-onset dementia. Dementia. 2019;18(5):1615–28. https://doi.org/10.1177/1471301217724026.
26. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. Gerontologist. 1990;30(5):583–94. https://doi.org/10.1093/geront/30.5.583.
27. Popok PJ, Reichman M, LeFeber L, Grunberg VA, Bannon SM, Vranceanu A-M. One diagnosis, two perspectives: Lived experiences of persons with young-onset dementia and their care-partners. Gerontologist. 2022;62(9):1311–23. https://doi.org/10.1093/geront/gnac050.

28. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health. 2000;23(4):334–40. https://doi.org/10.1002/1098-240X(200008)23:4.
29. Speziale HS, Carpenter DR. Qualitative research in nursing: Advancing the humanistic imperative. 4th ed. Lippincott Williams & Wilkins; 2007.
30. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57. https://doi.org/10.1093/intqhc/mzm042.
31. Walter E, Pinquart M. How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. Gerontologist. 2020;60(8):e609–19. https://doi.org/10.1093/geront/gnz118.
32. World Health Organization. (2023). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Figures

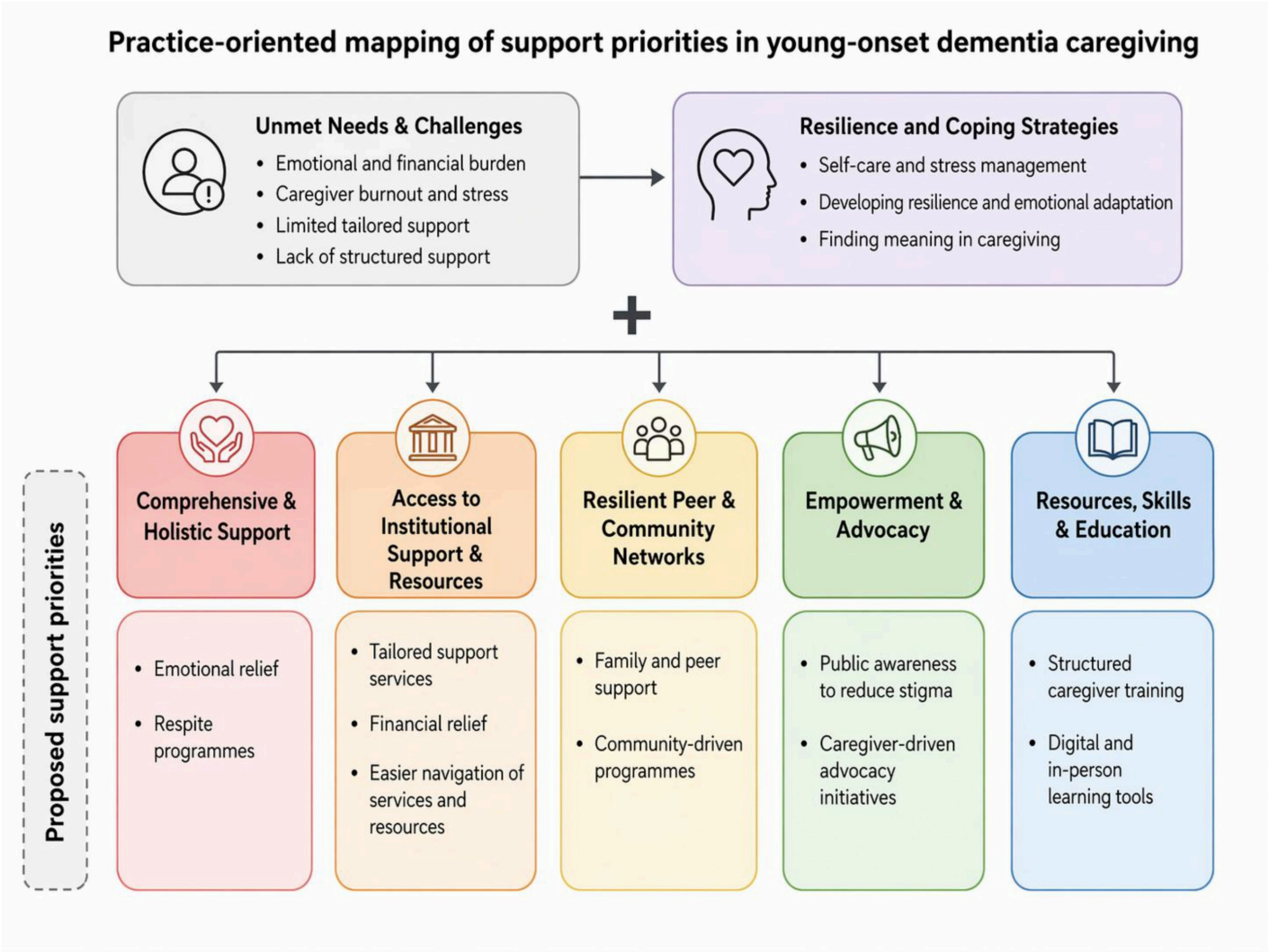


Figure 1: Practice-oriented mapping of support priorities in YOD caregiving

Figure 1

See image above for figure legend

Supplementary Files

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- AppendixA.docx