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Family Resilience in Young-Onset Dementia: A Qualitative Exploration of Coping, Adaptation, and Support

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ABSTRACT

Introduction: *Young-onset dementia (YOD) affects people before the age of 65 and places families in a caregiving situation that differs fundamentally from late-onset dementia, because it strikes during the peak of productive, parental, and financial life. Although family resilience is increasingly recognised as a determinant of caregiving sustainability, little is known about how families in Indonesian community settings construct that resilience.*

Methods: *A descriptive qualitative study was conducted in January 2025 in the catchment area of a community health centre (Puskesmas) in East Surabaya, Indonesia. Six family caregivers of people with YOD were recruited by purposive sampling, with recruitment stopping once data saturation was reached. Data were collected through in-depth semi-structured interviews (55-80 minutes) and analysed using Braun and Clarke's six-phase reflexive thematic analysis. Walsh's Family Resilience Framework served as a sensitising lens. Trustworthiness was established following Lincoln and Guba's criteria, and reporting followed the COREQ checklist.*

Results: *Participants comprised three spouses, two adult children, one sibling and one parent (aged 27-68 years) caring for relatives diagnosed at 39-56 years of age. Five themes were generated: (1) the unnamed journey towards diagnosis; (2) reconstructing meaning and rescaling hope; (3) restructuring the family: role flexibility and caregiver sustainability; (4) from silence and conflict to open conversation; and (5) surviving in the gaps of the support system. Across themes, families described resilience not as the absence of distress but as an iterative capacity to reorganise roles, renegotiate meaning, and keep relational bonds intact while expectations were repeatedly revised downwards.*

Conclusion: *Family resilience in YOD emerged as a relational and dynamic process rather than an individual trait. Nursing services in primary care should shift from a patient-only focus towards a family-unit approach that includes routine caregiver assessment, anticipatory and future-oriented family conversations, strength-preserving care strategies, a named care navigator, and YOD-specific peer support.*

INTRODUCTION

Dementia has long been positioned as a health problem for older people, but the scale and form of its burden transcends the traditional gerontological framework. The World Health Organization estimates that 57 million people worldwide were living with dementia in 2021, over 60% in low- and middle-income countries, with nearly 10 million new cases annually; dementia is now the seventh leading cause of death globally and a major contributor to disability and independence (World Health Organization, 2025). Behind these aggregate figures lies a crisis of care burden, borne largely by families, not by the formal care system.

What is often highlighted is that dementia is not exclusive to older people. Young-onset dementia (YOD), which is dementia with symptoms onset before age 65, is a distinct clinical and social entity. A global meta-analysis by Hendriks et al. (2021) found an age-standardized prevalence of 119.0 per 100,000 in the 30-64 age group, meaning approximately 3.9 million working-age adults worldwide are living with dementia. This estimate is approximately double the figures commonly cited (42 per 100,000 in the UK and 54 per 100,000 in Japan), confirming that YOD is systematically underestimated. Compared with the 57 million people living with dementia globally, this figure equates to approximately 6.8% of all cases—a far from marginal proportion for a condition that rarely falls under priority policy.

Incidence studies corroborate this picture. Hendriks et al. (2023) reported a global incidence of YOD of 11 per 100,000 person-years in the 30-64 age group, with a sharp gradient from 0.17 per 100,000 person-years in 30-34 age groups to 5.14 per 100,000 person-years in 60-64 age groups. Age-period-cohort analysis based on the Global Burden of Disease Study 2021 showed a steady trend: age-standardized prevalence in the population under 65 years increased from 93.39 per 100,000 (1990) to 96.09 per 100,000 (2021), and incidence from 16.24 to 17.16 per 100,000 (He et al., 2025).

The Indonesian context adds another layer of urgency. Estimates cited by Alzheimer's Disease International (2016) indicate that approximately 1.2 million Indonesians live with dementia, with projections increasing to over 4 million by 2050. Indonesia was the first country in Southeast Asia to launch a National Strategy for Alzheimer's Disease and Other Dementias in 2016 (Ministry of Health of the Republic of Indonesia, 2016). However, the strategy's implementation remains focused on the elderly population and lacks a dedicated service pathway for the young-onset group. Meanwhile, long-term care facilities in Indonesia are very limited, so almost all dementia care takes place at home and is supported by family members as informal caregivers (Theresia et al., 2023). A focus group study of dementia caregivers in Indonesia found that the community's low understanding of dementia creates a caregiving experience that inspires internalized stigma in the form of fear and shame, reinforced by misconceptions that dementia is caused by spiritual or mystical issues (Theresia et al., 2023).

In YOD, the burden of caregiving is exacerbated precisely by age. Onset during productive years means the disease strikes at a time when individuals are still the primary breadwinner, raising children, and still have long-term financial responsibilities. The chain of consequences is multifold: early job loss, loss of household income at a time when expenses are high, disruption to children's education, and the collapse of years of life plans. A systematic review of 37 studies summarizing the experiences of 566 informal caregivers with YOD showed that this group faces social role conflict, financial crises, and family breakdown at a different intensity than caregivers of older dementia (Lew et al., 2025). The review, including Kokorelias et al.'s (2024) review of 16 studies, identified the overarching theme of "decision-making," namely the need for family members to choose between their own occupational goals and caregiving responsibilities—a dilemma structurally rare for caregivers with later-onset dementia.

The journey to diagnosis is also more challenging. van Vliet et al. (2013) found that the average time between symptom onset and diagnosis in YOD was 4.4 years, compared to 2.8 years in later-onset dementia. During this 1.6-year gap, symptoms were often attributed to work stress, depression, or marital problems, resulting not only in delayed treatment but also in the erosion of family relationships before the disease even had a name.

Facing these multiple pressures, families remain challenged to persevere. However, resilience is not a passive state. Contemporary literature shifts focus from the burden on individual caregivers to the resilience of the family as a unit. Walsh (2016b) defines family resilience as the capacity of a family system to withstand and recover from disruptive challenges and organizes it into three key process domains: belief systems (making sense of adversity, positive outlook, transcendence, and spirituality), organizational patterns (flexibility, connectedness, and mobilization of social and economic resources), and communication processes (clarity of messages, open expression of emotions, and collaborative problem-solving). This framework emphasizes that resilience is not an innate trait of some “strong” families, but rather a process that can be learned and intervened (Walsh, 2016a).

Nevertheless, there are significant inconsistencies in the available evidence. First, most research on YOD originates from high-income countries in Europe, North America, and Australia, with established dementia service systems, social security schemes, and the availability of respite care—three factors largely absent in the Indonesian context. Second, the literature is still dominated by measures of individual caregiver psychological burden and distress, while adaptation processes at the family system level are much less frequently explored. Duangjina et al.'s (2025) integrative review of resilience among family caregivers of older adults with dementia in Asia confirms that research in this region remains limited and tends to adopt Western conceptualizations of individual resilience without considering the collective family structure of Asia. Third, studies explicitly using the family resilience framework in YOD populations are very few; One available study is Yang and Song's (2025) multiple case study in South Korea, which examined three family triads and demonstrated that family adaptation patterns can produce both resilient and non-resilient outcomes. Fourth, throughout the author's research, no Indonesian qualitative studies have been found that specifically explore family resilience in YOD in primary care settings.

This study was designed to address this issue. By exploring the experiences of families caring for patients with dementia (YOD) in a community health center (Puskesmas) in East Surabaya through the lens of Walsh's Family Resilience Framework, this study aims to generate a contextual understanding of how Indonesian families make sense of adversity, restructure care, communicate about the disease and the future, and negotiate support within a service system that does not yet offer a dedicated YOD pathway. The expected contribution is twofold: theoretically, extending Walsh's framework to the context of young-onset dementia in a middle-income country with a collectivist family structure; practically, providing an empirical basis for developing community-based family-centered interventions that are currently lacking in dementia services in Indonesia.

This study aims to qualitatively explore family resilience in caring for a family member with young-onset dementia, focusing on the coping, adaptation, and support processes experienced by families. Specifically, this study aims to: (1) describe how families make sense of and renegotiate difficult situations from pre-diagnosis to ongoing care; (2) identify patterns of family organization that support or hinder care; (3) describe communication and problem-solving processes within families; and (4) uncover unmet support needs from the family's perspective.

METHODS

Research Design

This study employed a descriptive qualitative design (a qualitative descriptive study) as conceptualized by Sandelowski (2000). This design was chosen because it yielded rich descriptions and remained close to the data (low-inference descriptions), without the theoretical transformations that stray from participants' language, as is common in interpretive phenomenology or grounded theory. Because the practical purpose of this study was to inform community resilience services, the proximity of the findings to the experiences narrated by participants was a primary consideration.

Walsh's Family Resilience Framework (2016b) was used as a sensitization lens (sensitization framework), rather than a rigid deductive coding framework. This meant that Walsh's three domains—belief systems, organizational patterns, and communication processes—formed the interview guide and served as references in the subsequent interpretation phase, while the development of codes and themes in the initial stages remained inductive from the data. This hybrid approach allowed findings not captured by Walsh's ecological framework, particularly the service dimensions and community stigma, to emerge as distinct themes.

The study was conducted in January 2025 in the working area of a community health center (Puskesmas) in East Surabaya, East Java, Indonesia. This area was selected because it has an active community-based geriatric health program, which documented cases of cognitive impairment during registration visits, although there was no specific program for young-onset dementia.

Participants and Sampling

Participants were recruited using purposive sampling through community health center visit data and referrals from community nurses and health workers. The sampling strategy aimed to maximize variation in kinship relationships, caregiver gender, and length of time since diagnosis, to capture a spectrum of experiences that was not limited to the spouse's perspective.

Inclusion criteria included: (1) a family member aged at least 18 years who lived in the same household or was actively and regularly involved in daily care; (2) caring for a family member with a medical diagnosis of dementia confirmed by a neurologist or psychiatrist, with symptom onset before age 65; (3) having been in a caregiving role for at least 6 months since diagnosis, thus having sufficient adaptation experience to narrate; (4) being able to communicate in Indonesian or Javanese; and (5) agreeing to and signing an informed consent.

Exclusion criteria included: (1) family members experiencing an acute health crisis, uncontrolled severe psychiatric disorder, or acute bereavement (less than three months post-loss), due to ethical and data quality considerations; (2) paid or non-family caregivers; and (3) family members whose involvement was limited to occasional visits without any caregiving responsibilities.

The final number of participants was six, not predetermined but rather following the principle of data saturation. Analysis was conducted parallel to data collection; after the fifth interview, no new substantive codes emerged, and the sixth interview merely confirmed existing codes, so data collection was discontinued. Adequacy was also assessed in terms of information richness (information strength): a small number of participants, highly relevant to the research objectives, with in-depth dialogue and a well-established theoretical framework, allowed for sufficient data collection in a smaller sample size.

Data Collection

Data were collected through in-depth, semi-structured, face-to-face interviews. Each participant was interviewed once, lasting 55–80 minutes (average 68 minutes), at their home or the community health center counseling room, depending on their preference, at a time that did not interfere with their treatment schedule. No third parties were present except at the participant's request.

An interview guide was developed based on the three domains of Walsh's Family Resilience Framework and the YOD literature, and then piloted with one caregiver outside the sample to assess clarity and flow of questions. The guide covered: (a) initial experiences recognizing change and the journey to diagnosis; (b) the meaning the family gives to illness and life changes; (c) role changes, division of labor, and relationship dynamics among family members; (d) communication patterns about illness, conflict, and the future; (e) sources of formal and informal support and unmet needs; and (f) participants' understanding of family strengths. Opening questions were narrative and open-ended (e.g., "Can you tell us how your family first realized something was different?"), followed by probing that was responsive to the participant's story line.

All interviews were recorded with written consent, transcribed verbatim, and supplemented with field notes on context, non-verbal language, and the researcher's impressions. Transcripts were returned to participants for review (transcript check) with the opportunity to correct, add, or withdraw statements. No participants declined participation or withdrew.

Data Analysis

Data were analyzed using Braun and Clarke's (2006) six-phase reflexive thematic analysis, with an inductive orientation in the initial phase and theory-informed interpretation in the later phase: (1) familiarization through repeated reading of transcripts and playback of audio recordings accompanied by initial notes; (2) line-by-line coding of the entire data set, generating semantic and latent codes; (3) searching for themes by grouping codes that share a core meaning; (4) reviewing themes by examining internal coherence across data extracts and the entire dataset, including an active search for deviant cases; (5) defining and naming themes accompanied by an analytical narrative; and (6) writing a report with the selection of the most representative illustrative quotes.

Coding was done manually using a matrix to maintain an audit trail. Once the inductive theme structure was established, cross-mapping was conducted across Walsh's three domains to assess the extent to which the findings aligned with or exceeded the framework. This formatting was interpretive and was not used to force data into theoretical categories.

Data Validity (Trustworthiness)

Data validity was established based on Lincoln and Guba's (1985) four criteria. Credibility was maintained through ongoing researcher involvement in the study area prior to data collection, transcript review, member checking of theme summaries by up to four willing participants, triangulation of source notes from field and community record nurses, and peer debriefing with two participants covering the lives and communities outside the data collection team to challenge the researcher's interpretations.

Transferability was pursued through thick descriptions of the context, participant characteristics, and care settings. Dependability was maintained through an audit trail documenting methodological decisions, codebook evolution, and dated reflexive notes. Confirmability is strengthened by the inclusion of adequate verbatim quotations for each theme as well as explicitly documented researcher reflexivity.

Researcher Reflexivity

The researcher is a female surgical lecturer with a clinical background and experience in community and gynecological surgery. She did not have a direct therapeutic relationship or structural power relationship with the participants prior to the study, and this was made clear at the beginning of each meeting to minimize the likelihood of participants providing answers deemed "expected." The researcher recognized that the blackout background could encourage a clinically solution-oriented understanding of the data, thus creating existential

meaning for the participants. To manage this, the researcher maintained a reflexive journal, recorded assumptions and emotional reactions after each interview, and clarified interpretations that "came too quickly" during peer debriefing sessions. Bracketing was not understood as an elimination of the researcher's position, but rather as a recognition and transparent management of it.

Ethical Considerations

This research has obtained ethical approval from the Health Research Ethics Committee of the Faculty of Health Sciences, Muhammadiyah University of Surabaya, and permits for implementation have been obtained from the Surabaya City Health Office and the head of the relevant Community Health Center. All participants received verbal and written explanations of the purpose, procedures, benefits, risks, and right to consent at any time without consequences to the services they received. They also provided written informed consent prior to the interview, with separate consent for audio recording.

RESULTS

Six family members participated, consisting of a wife, a husband, two adult children, one sibling, and one parent. Participants ranged in age from 27 to 68 years, patients from 39 to 56 years, and the time since diagnosis from 1.5 to 4 years. Full characteristics are presented in Table 1. This variation in kinship positions is analytically important because it yields three distinct structural configurations: spouses who lose both a life partner and a financial partner (P1, P3), adult children experiencing a generational role reversal while establishing their own lives (P2, P6), and families of origin reassuming responsibility for independent adult members (P4, P5).

Thematic analysis yielded five themes and twenty-two subthemes. The structure of the themes and their mapping to the domains of Walsh's Family Resilience Framework are presented in Table 2. The five themes do not stand as separate categories, but rather form a process trajectory: experiences throughout the pre-diagnosis period (Theme 1) become a starting point that forces the family to reconstruct meaning (Theme 2), which then allows for a restructuring of the care structure (Theme 3), facilitated by changes in communication patterns (Theme 4), while the entire process takes place in an inadequate ecology (Theme 5).

Table 1. Characteristics of respondent study

Participant	Relationship to Patient	Participant Age (years)	Patient Age (years)	Time Since Diagnosis	Caregiving Role
P1	Wife	48	52	± 2 years	Primary caregiver
P2	Daughter	27	55	± 3 years	Co-caregiver with father
P3	Husband	58	51	± 1.5 years	Primary caregiver
P4	Older brother	46	43	± 2 years	Sibling caregiver/support
P5	Mother of the patient	68	39	± 4 years	Primary caregiver with daughter-in-law
P6	Son	32	56	± 2.5 years	Family caregiver with mother

Table 2. Themes, Subthemes, and Mapping to the Domains of Walsh’s Family Resilience Fra

Theme	Subtheme	Walsh Domain
1. The Unnamed Journey Toward Diagnosis	(a) Normalizing early symptoms as fatigue and work-related stress; (b) A turning point in the workplace; (c) The shock of diagnosis and disruption of life plans	Pre-resilience context (adversity appraisal)
2. Reconstructing Meaning and Rescaling Hope	(a) Accepting without giving up; (b) Narrowing the time horizon to “today”; (c) Recalibrating hope; (d) Separating the illness from self-worth; (e) Spirituality as a source of strength	Belief systems
3. Restructuring the Family: Role Flexibility and Caregiver Sustainability	(a) Reversed and blurred roles; (b) Distribution of caregiving burden and caregiver rotation; (c) Preserving caregivers’ own capacity; (d) Emotional ambivalence and guilt; (e) Financial and occupational vulnerability	Organizational patterns

4. From Silence and Conflict to Open Conversation	(a) Denial and conflict as an initial phase; (b) Naming the illness to children and others; (c) Anticipatory conversations about the future; (d) Empowering support rather than taking over	Communication and problem-solving processes
5. Surviving in the Gaps of the Support System	(a) Age-related stigma and misconceptions; (b) Symbolic versus instrumental support; (c) Fragmented information and the need for navigation; (d) The need for YOD-specific peer support; (e) Invisible caregivers within services	Ecological context (community and system resources)

Theme 1: The Unnamed Journey to Diagnosis

All participants described the period before diagnosis as a confusing phase, when the changes they observed didn't yet have a name and therefore couldn't be meaningfully addressed. Early symptoms were consistently attributed to workload, not pathology; the patient's young age was often used as a reason for not having dementia.

"At first, we thought it was just because he was overworked. My husband was still working at the time and often forgot little things. For example, he'd forget to put the keys in, forget meetings, or repeat the same questions. I didn't think it was anything serious at first either." (P1, wife, 48 years old)

The realization that the problem was more serious generally came not at home, but when functional failure occurred at work—a context that typically distinguishes YOD from later-onset dementia, as the patient was still actively working.

"When he suddenly couldn't follow his usual procedures, we started to worry. He even got lost on his way home from work. He'd been walking that way for years." (P1, wife, 48 years old)

The diagnosis wasn't experienced primarily as medical information, but as the collapse of the family's projections of the future. What stood out most in the participants' narratives wasn't the disease itself, but rather the sudden loss of life plans.

"When the doctor said dementia, it felt like everything stopped. My biggest concern wasn't just the disease, but the future of the family. We still have children in college. My husband is too young to have such a disease." (P1, wife, 48 years old)

P5 shared a similar sentiment from a parental perspective: "As a mother, I always imagined my children would live long, work, and develop the world. Suddenly, all those plans changed." P3 added a dimension of epistemic incomprehension—not just not knowing what to do, but having no framework to understand that this condition could occur at such a young age: "I also don't understand how someone so young could develop dementia."

Theme 2: Reconstructing Meaning and Rescaling Hope

This theme captures the shift in the family's belief system from a recovery orientation to an orientation of presence and connectedness—an iterative process that participants narrated as "learning." Participants explicitly distinguished acceptance from resignation; acceptance, in fact, became a framework for adaptive action.

"*Accepting illness doesn't mean giving up. We accept that mom is sick, but we still find ways to make family life work." (P2, daughter, 27 years old)*

The most consistent meaning-making strategy was the deliberate temporal shortening of the natural landscape. Long-term planning, previously a source of order, became a source of suffering; the family responded by shifting focus to a single, daily moment.

"We used to always plan for the next five or ten years. Now we focus more on what we can do today. If today she can still eat with us and joke around, we enjoy that." (P1, wife, 48 years old)

P5 developed a similar defensive strategy: "I've learned not to think too far ahead. If I keep thinking about the future, I get very sad. So I focus on today's needs."

Hope wasn't abandoned, but rather scaled down to a realistic goal. P4 articulated this while emphasizing that the family let go of expectations of recovery without losing direction.

"We don't expect her illness to go away. Our hopes are simpler: that she stays safe, stays connected to her family, and still feels valued." (P4, older brother, 46 years old)

Another strategy that sustains long-term relationships is conceptualizing the relationship between changes caused by illness and the person's moral identity, so that relational commitment can be maintained even if the partner's behavior changes drastically. For P4, this goes hand in hand with a shift in expectations: "We used to think she should go back to the way she was before she got sick. Now we're more realistic. We look for the abilities she still has."

"Even though she's changed, she's still my wife. I remember that it's her illness that's changed, not her value as a person." (P3, husband, 58 years old)

For the oldest participants, religious practices and small signs of patient well-being were sources of comfort: "Praying and talking with family. I also feel calmer when I see my child can still smile." (P5).

Theme 3: Restructuring Family Structures — Role Flexibility and Caregiver Sustainability

This theme encompasses changes at the structural level: who does what, how the burden is distributed, and how caregiver capacity is maintained. The three kinship configurations demonstrate different forms of role reversal that equally disrupt established arrangements; within couples, the boundaries between intimacy and caregiving become blurred.

"We used to share the housework. Now I do almost everything. I also have to organize medications, remind him of his schedule, and supervise him when he goes out. I feel like both a wife and a caregiver." (P1, wife, 48 years old)

A similar pattern emerges across generations. P2 said, "My mother used to take care of me. Now I remind her to take her medication, accompany her to check-ups, and help with administrative matters." The most striking reversal was narrated by P5, who returned to caring for her 39-year-old child: "My child, who used to help me, now needs my help." For P6, the most difficult loss was not the father's instrumental abilities but his authoritative position — "He was always the one who made the family decisions. Now he sometimes gets confused about even simple things."

Families that successfully maintained long-term care were those that transformed care from a single responsibility into a multifaceted system, ranging from informal to explicitly structured.

"We started to divide the tasks. One person takes care of the finances, one person accompanies the check-ups, and I take care of things related to work and housing." (P4, older brother, 46 years old)

P5 described a more informal approach — *"My daughter-in-law is very helpful. We take over when one gets tired" — while P2 interpreted awareness of one's limits as a learning experience that dictates caregiving, not neglect: "I learned that I don't have to be available 24/7. If I keep pushing myself, I won't be able to help my mother properly."*

Self-care emerged as a self-learned practice, not one facilitated by services. P3 developed a new routine and maintained a minimal social support network:

"I started walking in the morning. I never used to exercise. Now I find it helps. I also have a friend I can call when I'm feeling really tired." (P3, husband, 58 years old)

The most vulnerable point in the participants' narratives was their struggle with negative emotions they deemed inappropriate: fatigue and anger coexisted with guilt for feeling them.

"Sometimes I feel guilty when I feel tired or angry. Because I know he doesn't do it on purpose. But people have limits. There are times when I want to be a wife again, not just a caregiver." (P1, wife, 48 years old)

P2 described her generational version: *"Sometimes I feel selfish when I think about my career or my life. But then I realize I'm still young and have to live my life."* P3 revealed moments of doubt about longing, which were then tempered by the lack of alternatives: *"Especially when I'm sleep deprived and my wife keeps asking the same questions. I've thought, 'I don't know how long I can do this.' But then I feel like if not me, who will?"* This statement demonstrates that apparent resilience does not always stem from adequate resources, but sometimes from a lack of choice.

A characteristic dimension of YOD is the disruption to productive life for both patients and caregivers. A patient's job loss not only impacts their financial well-being but also destroys their self-esteem.

"My younger sibling is actually still of productive age. He lost his job, and it affected his self-esteem. He often said he felt useless." (P4, older brother, 46 years old)

P4 also addressed the structural consequences: *"Families with young patients face financial challenges because patients lose their jobs early."* For caregivers, occupational impacts manifest as delayed aspirations *(P2: "I'm still working and actually want to continue my education. But I often wonder if I can afford to be away from home")* and as compromises to ongoing work *(P6: "I've had to take time off work several times to accompany my father to the hospital. As long as my job is flexible enough").* P6 also voiced long-term structural concerns: *"I wonder who will care for my father when his needs become greater."*

Theme 4: From Silence and Conflict to Open Conversation

This theme depicts communication as a driving mechanism for the condition, with a recurring pattern of shifting from denial and conflict to shared deliberation. Disagreements between family members regarding the reality and meaning of symptoms became a significant source of tension in the early stages.

"Initially, there were frequent conflicts. My father denied my mother's condition. He said she was just stressed or thinking too much. My father and I often disagreed about what to do." (P2, daughter, 27 years old)

Conflict also emerged in the form of struggles for decision-making authority (*P4: "Sometimes family members feel that I interfere too much"*) and differences in care philosophies (*P6: "My mother is very protective. I sometimes feel that she does too much for him"*). Conflict resolution was not achieved through a single event, but through a combination of professional education and experiential evidence: *"Education from the doctor and our own experience. Once my father saw that my mother's problems were becoming clearer, he began to accept them. Now we discuss them more often before making decisions." (P2).*

Families that adapt better are those that name the situation and communicate it explicitly, including to their children, so that behavioral changes are not interpreted as deliberate.

"I also explain to my children that their father is sick, not that he's acting like that on purpose. We divide the tasks. If I'm tired, my children help take care of their father." (P1, wife, 48 years old)

Openness to the environment develops over time and has tangible social consequences. P5 described a shift from shyness to active explanation, which then led to support from neighbors:

"Now I'm more confident in explaining. I used to be embarrassed. Now I think if we don't explain, people won't understand. Some neighbors have started to help. They know that when my child leaves the house, he can sometimes get confused. They also help remind us." (P5, patient's mother, 68 years old)

The ability to talk about scenarios that haven't yet occurred—costs, follow-up care, sharing responsibilities—was narrated as a source of strength, even though it was initially avoided because it was painful.

"We used to avoid talking about the future because it felt too painful. Now we're starting to talk about finances, care, and who can help... Because we're no longer facing problems as something unexpected. We're starting to prepare ourselves." (P6, son, 32 years old)

Another important conceptual shift is the understanding that excessive help actually accelerates the loss of a patient's abilities and dignity.

"We've come to understand that helping doesn't mean doing everything for the patient. It means giving him the opportunity to do the things he can still do." (P2, daughter, 27 years old)

"At first, I tried to take over everything. But then I realized that it made Dad feel like he was losing control. So now I give him choices. For example, 'Do you want to eat now or later?' instead of just deciding everything." (P6, son, 32 years old)

The same principle was expressed by P4 in terms of dignity — *"We don't want everyone to treat him like a child"* — and by P2 through an inventory of his remaining abilities: *"He can still cook simple meals, watch his favorite shows, and talk to his grandchildren."* P3 added a technical dimension to communication: *"I used to argue... Now I try not to argue. I change the subject or give him time to calm down."*

Theme 5: Surviving in the Gap of Support Systems

The fifth theme places the entire adaptation process within an unsupportive ecological context; the resilience demonstrated by participants was largely self-constructed, outside of, and not through, the service system. The most frequently cited barrier was the societal belief that dementia only occurs in old age, which makes the family's experience difficult for others to understand.

"People around us are actually fine, but they don't understand the disease. They sometimes say, 'You're still young, how can you forget?'" (P5, patient's mother, 68 years old).

P1 echoed this sentiment: *"Many people don't understand dementia at a young age. They think it only happens to older people." Stigma also drives a strategy of spectrum concealment based on fears of patient devaluation: "We don't always tell people. Sometimes I'm afraid people will see my mother as someone who can't do anything. But there's still so much she can do." (P2).*

Participants also made a sharp distinction between verbal sympathy and tangible assistance; the support available tends to be limited to symbolic ones.

"I feel alone. People often say, 'Be patient, okay?' But caregivers actually need more than that. Sometimes I just want someone to come and take over for me and take care of my wife for a few hours." (P3, husband, 58 years old)

This statement is the most explicit articulation of the need for respite care in the data and highlights the absence of such services at the community level. P3 also described the limitations of extended family support, which is remote: "Some families live far away. They care, but they don't really see what's going on day-to-day."

Participants' information needs went beyond pharmacological information and practical daily skills and long-term planning.

"Clear information. Not just about medications. We need to know how to deal with behavioral changes, how to stay safe, how to plan for the future, and how caregivers can take care of themselves." (P1, wife, 48 years old)

P3 emphasized the need for operational guidance: "Doctors explain some things, but I think

families also need concrete examples. For example, what to do when the patient is angry, refuses to bathe, or refuses to take medication." P6 identified a more structural problem, namely the fragmentation of information sources and the absence of an integrated source:

"Sometimes families get information from doctors, nurses, the internet, and other people, but it's all separate. We need someone to help connect it all." (P6, boy, 32 years old)

P5 voiced the need for continuity and accessibility of services beyond structured visit schedules: "I want someone we can call when problems arise at home. Not just come to check-ups."

The youngest participant articulated sharply why generic peer support is inadequate for YOD families.

"I want a support group specifically for families with young-onset dementia. Because our problems are different from families caring for older adults with dementia. We still work, still have small children, still have to worry about education and finances." (P2, girl, 27 years old)

The most direct criticism of service practices included the exclusive focus on the patient, which meant that caregiver well-being was never systematically assessed.

"Don't just focus on the patient. Ask about the caregiver's condition, too. Sometimes caregivers seem fine, but are actually very tired." (P3, husband, 58 years old)

DISCUSSION

The main findings of this study demonstrate that family resilience is not a condition one has or lacks, but rather an iterative process built through the reconstruction of meaning, the restructuring of role structures, and shifting communication patterns—three processes that occur simultaneously and mutually reinforcing each other within a very limited ecological support system.

The first theme confirms that the journey of family resilience begins long before diagnosis. The normalization of early symptoms as work burnout aligns with the quantitative evidence of van Vliet et al. (2013) regarding the 4.4-year interval between symptom onset and diagnosis in YOD, compared to 2.8 years in later-onset dementia. What this finding adds is the experiential texture of the 1.6-year gap: not simply a matter of administrative delay, but rather a period when the family lives with an unaltered reality that cannot be addressed collectively.

The discussion is relational. Denial by one family member (P2) and epistemic misunderstanding (P3) emerge precisely in the pre-diagnosis period. Within Walsh's (2016b) framework, this is the phase of establishing an appraisal of the distress: without a shared explanation of what is happening, the family cannot build a coherent belief system, and without it, role reorganization is difficult. Consequently, family resilience interventions should not begin after diagnosis but rather during the diagnosis-seeking phase, and diagnostic delays in YOD need to be understood as a family issue, not simply a matter of clinical accuracy.

The turning point in awareness that occurs in the workplace is consistent with the structural nature of YOD reported by Lew et al. (2025) in their review of 37 studies, namely social role conflict and financial crisis as distinctive markers of this population. Because Indonesia does not yet have an employment investment mechanism for workers with cognitive impairments, failure in the workplace often results in immediate termination of employment without a transition path, as experienced by P4's younger sibling.

The second theme reflects Walsh's (2016b) belief system, which positions meaning-making toward adversity, positive outlook, and transcendence as the "heart and soul" of resilience. Three strategic meanings deserve special attention. First, the clear distinction between acceptance and resignation (P2) challenges clinical visualizations that sometimes equate a diagnosis of acceptance with decreased care engagement; in these data, acceptance instead functions as a coping measure. Second, the deliberate shortening of the temporal horizon (P1, P5) can be read as meaning-based emotion regulation, where long-term planning shifts from a source of control to a source of anticipatory suffering. Third, the conceptualization of illness and the caregiver's self-worth (P3) maintains relational identity continuity and enables commitment to care to endure.

The recalibration of hope articulated in P4—from recovery to safety, connectedness, and esteem—is consistent with Zhang et al.'s (2025) meta-synthesis emphasizing the importance of maintaining meaning, role, and dignity, rather than simply managing symptoms, and provides an empirical basis for shifting care orientation from a deficit model to a residual capacity-based model. The spiritual dimension of P5 needs to be read within the Indonesian cultural context: Duangjina et al. (2025) stated that caregivers' resilience resources in Asia are often diminished by religious values and familial obligations, so conceptualizing resilience solely in terms of individual risk does not capture the mechanisms that truly operate. In this data, prayer and religious meaning are not refugees but rather actively mobilized resources.

The third theme maps Walsh's domain of organizational patterns. The most consistent finding

is that families who are able to sustain long-term care are those who successfully transform care from a single responsibility to a distributed system (P2, P4, P5). In contrast, P3's narrative as a single caregiver with a distant extended family displays the most obvious signs of exhaustion, including condemnation of desired desires. This contrast is similar to the pattern reported by Yang and Song (2025) in South Korea, where family adaptation patterns can produce both external and non-existent resilience depending on the family's internal dynamics.

P3's statement—"If not me, who?"—should not be read as an indicator of resilience, but rather as persistence based on the lack of alternatives. This distinction is clinically important, as caregivers who persist out of choice risk sudden collapse when their capacity is exceeded. These findings warn against the romanticization of caregiver resilience in healthcare discourse, especially when such resilience is actually a product of a system of absence.

Emotional ambivalence accompanied by guilt (P1, P2) is recurrent in the caregiver literature, but in the case of the YOD, it has an additional characteristic. For spouses, guilt stems from the loss of an intimate relationship that should have lasted decades (P1: “There are times when I want to be a wife again”). For adult children, it stems from the conflict between filial obligations and their own developmental stage (P2)—remaining within the theme of “occupational decision-making” identified by Kokorelias et al. (2024), where family members are forced to choose between educational or career goals and caregiving responsibilities. In the Indonesian context, where the norm of filial piety is strong and caregiving is largely focused on female family members (Theresia et al., 2023), these tensions are likely greater and more difficult to articulate. Meanwhile, the self-care practices that independently develop P3 indicate that caregivers are able to identify their own needs but lack the support to systematically maintain them—an opportunity for low-cost interventions that legitimize and sustain strategies that have emerged organically, rather than creating new ones. The fourth theme identifies communication as a driving mechanism linking meaning to action, with an iterative journey from denial and conflict to collective deliberation. The idea of change is not a single process, but rather a combination of professional education and accumulated experiential evidence (P2). This indicates that a single family education session at diagnosis is insufficient; education needs to be repeated and synchronized with moments when the family has concrete experiences to relate to.

Anticipatory conversations (P6) have high practical relevance: families who begin discussing financing, follow-up care, and the allocation of responsibilities report a reduction in the “sudden” nature of emerging crises. This represents an early form of advance care planning undertaken by families without professional facilitation. Given that Ritzen et al. (2025) demonstrated that the needs of families with OCD vary substantially according to disease stage and living arrangement, facilitating anticipatory conversations by community nurses in the early-to-middle phase is a timely intervention.

The subtheme with the greatest potential for practical messages is the reframing of support: from “doing for” to “providing opportunities.” P2 and P6's articulation of the dangers of over-taking aligns with the principles of capabilities-based care emphasized by Zhang et al. (2025). P6's practice of offering limited choices rather than prescribing—"Do you want to eat now or later?"—and P3's strategy of redirecting the conversation rather than confronting false beliefs are both clinically effective techniques, but in this data, they were discovered independently through trial and error, not through educational services. The gap between the practical knowledge families need and what services provide is the most actionable finding of this study.

Age-based stigma—summarized by the phrase "You're still young, how could you forget?"—was the most frequently cited challenge. This finding aligns with research by Theresia et al. (2023) on dementia caregivers in Jakarta, which found that low dementia literacy in the community led to internalized stigma in the form of fear and shame, reinforced by spiritual and mystical attributions to symptoms. In YOD, this stigma is twofold: stigma against dementia itself, coupled with disbelief that the condition is possible at such a young age. P2's concealment of the course was a rational response to the risks of evaluation, but came at a high cost, cutting off the family's access to informal support.

The contrast between P2's concealment and P5's openness provides valuable insights. P5's openness not only reduced psychological burden but also generated a concrete resource in the form of neighbors' awareness of the patient's risk of getting lost. Disclosure of diagnosis in Indonesian communities with strong neighborhood cohesion has the potential to transform social environments into informal safety networks—a resource unique to collective contexts that is rarely available in urban settings at high altitudes, making it a worthy target for community-based interventions. P3's distinction between symbolic and instrumental support is the most explicit articulation of the need for respite care in the data. Theresia et al. (2023) noted that respite care for informal caregivers is underdeveloped in Indonesia, and this finding confirms that its absence is directly felt as isolation. P6's expressed need for a

care navigator aligns with international literature on the fragmentation of YOD services, yet this role is undefined within any Indonesian primary care structure. Similarly, P2's argument for the need for YOD-specific peer support groups is a lay formulation that appropriately captures the structural differences documented by Kokorelias et al. (2024) and Lew et al. (2025); incorporating YOD families into elderly dementia support groups risks creating a mismatch in experiences that could actually reinforce a sense of protection. Finally, P3's critique that services only inquire about the patient's condition suggests that the unit of concern in current practice remains the individual, whereas Walsh's (2016a) framework suggests that effective interventions target family processes.

Implications for Nursing Practice

These findings lead to five practical implications at the primary care level. First, caregiver assessments should be instituted as a routine part of every service contact; brief instruments assessing fatigue, sleep quality, emotional distress, and the availability of substitute support could be requested during community health center (Puskesmas) visits and home visits. Second, family education should include pharmacological information and practical, scenario-based skills—coping with agitation, self-care refusal, risk of disclosure, and autonomy-preserving communication—because the concrete example-based format suggested by P3 is likely more effective than conceptual instruction. Third, community nurses can facilitate structured family meetings to discuss role allocation, caregiver rotation, and anticipatory planning; these meetings directly address Walsh's organizational and communication domains and have the potential to prevent conflicts that emerged in nearly all families in this data set. Fourth, the role of care navigator should be developed within the primary care structure, with the function of integrating information across sources, serving as a point of contact outside of scheduled appointments, and connecting families with social resources. Fifth, peer support groups specifically for those with dementia should be initiated, given the substantial differences in needs of this group from those of families of older people with dementia. At the policy level, these findings support the expansion of the National Strategy for Alzheimer's Disease and Other Dementia Management (Ministry of Health of the Republic of Indonesia, 2016) to explicitly include young-onset dementia service pathways, including employment protection, social security access for productive-age patients who lose their jobs, and community-based respite services.

Study Limitations

Several limitations need to be considered. First, participants were limited to six individuals from a single urban community health center (Puskesmas) coverage area, so transferability to rural contexts or areas with different service structures needs to be carefully assessed. Second, data were collected from the perspectives of family members only; the voices of individuals with YOD were not included, despite the evolving literature on the importance of dyadic and triadic perspectives.

Future research is recommended to use dyadic or triadic designs that include individuals with YOD, their partners, and adult children in a single unit of analysis; employ longitudinal designs to explore resilience trajectories across the disease trajectory; expand sampling to rural and cross-ethnic areas in Indonesia; and develop and test family breakdown interventions based on the Walsh framework tailored to the Indonesian primary care context.

CONCLUSION

This descriptive qualitative study found that family resilience in caring for a family member with young-onset dementia is a relational process built gradually, not an inherent trait that some families possess from the outset. The five themes that emerged—the anonymous journey of diagnosis, the reconstruction of meaning and the re-scaling of expectations, the restructuring of family structure, the shift from silence and conflict to open conversation, and the struggle to persevere through gaps in support systems—depict a trajectory of adaptation that begins with pre-diagnosis transmission and continues through meaning-making, role reorganization, and ongoing communication negotiations.

The third domain of the Walsh Family Resilience Framework proved relevant in the Indonesian context, but operates sequentially and conditionally, requiring an explicit ecological dimension. In service systems that do not yet provide dedicated YOD pathways, respite care, or appropriate peer support, the resilience displayed by families is largely the result of their own work—and is therefore fragile. The persistence of a single caregiver who persists in the absence of alternatives should not be mistaken for successful adaptation.

Participants defined family strength not as the absence of suffering, but as the ability to change ways of life without losing connection to one another. This formulation should serve as the orientation for community hosting services: a shift from a solely patient-focused approach to a family unit approach that includes routine caregiver assessments, scenario-based practical skills education, facilitation of family meetings and

anticipatory planning, availability of care navigators, and the development of peer support groups specifically for young-onset dementia.

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