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Research article

The influence of caregivers' lived experiences in decision-making processes on care transitions in young-onset dementia

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Abstract

Background: Caregivers of people with young-onset dementia (YOD) hold diverse perspectives on the caregiving trajectory, reflecting the heterogeneity of underlying etiologies and the life stages of these people, who are often in the midst of employment, child-rearing, and other social responsibilities. Post-diagnostic care and services are often suboptimal and caregivers tend to be hesitant to initiate formal care and support services. We refer to movements of persons between different levels of care or physical locations as care transitions.

Objective: To improve caregiver support, this study aimed to provide insights into caregivers' perspectives on the decision-making process regarding care transitions and associated barriers and facilitators.

Methods: Seventeen interviews with six caregivers of people with YOD were analyzed. Inductive content analysis was used to generate codes, followed by constant comparative analysis to create categories and themes describing caregivers' experiences.

Results: Barriers and facilitators influencing the decision-making process related to the initiation of care transitions were identified at two themes: individual and contextual level. Six categories and 23 sub-categories emerged. Individual-level categories included the character traits of the caregiver, the caregiver's need for support, impacts on the quality of the caregiver's relationship, and the burden experienced by the caregiver. Contextual-level categories included the social environment and the caregivers' experiences with healthcare professionals.

Conclusions: Caregivers' decision-making regarding care transitions is shaped by thinking processes, character traits and contextual aspects. Healthcare professionals should strengthen collaboration and communication with caregivers. Acknowledging grief and supporting caregivers'sense of control are essential to providing adequate support.

Keywords
Alzheimer's disease, caregiver burden, care pathways, post-diagnostic, qualitative research, support

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Introduction

Dementia that manifests itself in individuals younger than 65 years is defined as young-onset dementia (YOD).[1] The global prevalence and incidence of YOD are relatively low, at 119 per 100,000 individuals[2] and 370,000 newly diagnosed cases annually worldwide, respectively.[3] However, diagnostic delays associated with YOD occur frequently due to faulty diagnoses or misattribution of symptoms,[4] a large variety of possible causes of YOD,[1] and an atypical symptom presentation in young individuals.[5] On average, anywhere from 3.2–5.5 years elapses between

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the occurrence of first YOD symptoms and an appropriate diagnosis.[6,7] Recent research has shown that the age at which YOD is diagnosed ranges from 37–69 years, with Alzheimer's disease (70.1%), frontotemporal dementia (11.1%), and Lewy body dementia (5.1%) being among the most frequently occurring subtypes in the Netherlands.[8] Recent prospective epidemiological research further estimates that between 14,655 and 20,340 people were living with YOD in the Netherlands in 2021, with an age-standardized incidence of approximately 24 new cases per 100,000 individuals aged 30–69 years annually.[9]

Beyond the considerable diversity in etiologies and the complex diagnostic process, spouses of people with YOD are often the primary caregiver and they can experience significant difficulties depending on their particular phase of life.[10] Such young caregivers often face multiple responsibilities, including employment and managing a household, which often prove challenging to reconcile with their caregiving duties.[11]

A range of factors that impact the burden experienced by caregivers of people with YOD have been identified in the literature. For instance, age-appropriate services are often unavailable or only available at large geographical distances, which may exacerbate caregiver burden as well as the experience of social and psychological stress.[12] Over and above this, caregiver burden might increase due to difficulties in accepting the diagnosis, and also when higher levels of behavioral symptoms were reported in the person with YOD.[13,14] Other aspects of YOD that influence the perceived burden of caregivers include apathy, disinhibition and the severity of the disease.[14] Caregiver burden, depression, anxiety and hopelessness have been found to be negatively associated with caregiver quality of life.[15] Many causes of burden are experienced by both the caregiver and the person with YOD.[16] Additionally, caregivers often report ambiguous feelings during the caregiving trajectory as they experience feelings of loss and grief while their loved one is still alive.[17] During the caregiving trajectory, caregiver perspectives can change and caregivers often experience stigma and embarrassment, which may decrease their social interactions with family and friends.[18] Factors such as exhibiting protective behavior towards the person with YOD, role changes and changes in future perspectives can negatively affect the quality of relationships over time.[19,20] Having a more positive attitude towards their role might help caregivers cope with relationship changes, particularly when reciprocity diminishes.[20] Caregivers require support in which they can participate with the person with YOD; this situation is particularly true shortly after a diagnosis.[21] Although the aforementioned aspects appear to explain caregiver perspectives, little is known about how these factors evolve throughout the caregiving trajectory and how they influence one another.

Besides factors affecting the burden that caregivers experience, caregivers are also charged with providing care and support for their loved ones which includes initiating care transitions, such as arranging a case manager, day care, respite care, or admission to a long-term care facility. Care transitions are defined as anticipated movements of persons between different levels of care or different physical locations.[22] During the decision-making process regarding the initiation of care transitions, caregivers often choose to continue providing care themselves rather than seeking support from healthcare professionals.[23] Services for people with YOD, such as specialized case managers, age-specific day care, specialized care units within long-term care facilities, and programs aimed at enhancing team expertise through staff training, are rarely available and often poorly integrated within healthcare systems.[12,24] Ideally, such services should be family-focused, better coordinated across the health, aged care, and disability sectors, and extend their reach to the education, social welfare, and child protection systems.[24] The lack of such comprehensive and integrated support hinders the initiation of appropriate care at the time it is needed. Furthermore, caregivers' experiences with those services can vary.[25] Another reason that caregivers might postpone the initiation of formal care is the 'early-stage needs paradox'.[26] That paradox pertains to caregivers stressing the need for help in the early stages of the caregiving trajectory, but only upon reflection in hindsight. The recognition of increasing care needs or burden at an earlier stage could have resulted in more timely and adequate service planning. Furthermore, relatively little is known about decisions regarding care transitions in YOD.[27]

The timely initiation of appropriate care and specific knowledge as to how such support can best be arranged is important to support people with YOD and their families. Little is known about the experiences and motives regarding the initiation of formal care by YOD caregivers and how caregivers experience care transitions within the context of the caregiving trajectory. Therefore, this study aimed to provide insights into caregivers' perspectives on the decision-making process regarding care transitions and, more specifically, the barriers and facilitators they experienced during this process.

Methods

We explored previous conducted interviews with caregivers of people living with YOD. The results were reported according to the 32-item checklist of the consolidated criteria for reporting qualitative research (COREQ)[28] (Supplemental Material 1).

Study design and setting

We used data from the longitudinal two-year cohort of the Dutch Needs in Young-onset Dementia (NeedYD) study,

with details on participant selection and recruitment described in the study's protocol article.[29] The NeedYD study followed 215 dyads of people with YOD and their caregivers. The dyads were assessed at six-months intervals at the caregivers' preferred location (mostly at home), using assessments, quantitative interviews, questionnaires and cognitive tests. In addition, qualitative interviews with the caregivers were conducted every twelve months (Supplemental Material 2). Primary objectives of the NeedYD study included exploring the characteristics and care needs of both young people living with dementia and their caregivers, the perspectives of caregivers on the caregiving trajectory in YOD, and the course of neuropsychiatric symptoms together with their possible risk factors. Participants were recruited through Dutch memory clinics in Amsterdam, Nijmegen and Maastricht, regional hospitals, mental health services and YOD-specialized day care facilities.[29] The protocol of the NeedYD study was approved by the Medical Ethics Committee of Maastricht University Medical Center, the Netherlands (MEC 07-2-38) and includes the approval for future use, with due consideration of GDPR legislation. This study adheres to the principles stated in the 'Declaration of Helsinki'. All participants provided written informed consent prior to participation and written consent to publish the data obtained from them.

Procedures and data collection

Interviews with each primary caregiver (spouse) lasted between 20 and 50 min. The interviews were conducted by trained researchers. The interviews were audiotaped and then transcribed. Each interview started with open-ended questions regarding the caregiver's experiences, care needs and future prospects; time was allotted for expansion or clarification. Purposeful sampling was used to identify the interviews with the most relevant content for current study,[30] based on the following criteria concerning the person with YOD: (1) inclusion in the study shortly after diagnosis; (2) the initiation of two care transitions: the start of day care or daytime activities, and admission to a nursing home, during follow-up, i.e., between the first and third interview, two years later; and (3) participation in all of the qualitative interviews until the conclusion of the study (Figure 1).

Data analysis

The interviews were transcribed verbatim, to capture and incorporate all verbal and vocal information, and analyzed independently by two trained researchers (DvdV and BS) in 2023 and 2024. We performed inductive content analysis[31] using Atlas.ti.[32] The analysis was exploratory and aimed to identify patterns of meaning across caregivers' narratives regarding care transitions, rather than to examine predefined factors or differences between groups. As first step, we used open coding[30] to identify quotes containing considerations, experiences and feelings regarding care transitions throughout the caregiving trajectory. Next, those codes were compared with the rest of the data to establish sub-categories using constant comparative analysis.[33] After the first six interviews, a consensus meeting with an independent researcher (KP) was held to compare codes and discuss sub-categories. The inductive content analysis was continued in the following interviews until data saturation occurred and no new codes emerged. Finally, DvdV and BS identified the themes and categories that captured the sub-categories.[31] These results were discussed with two independent researchers (KP and CB), and consensus was attained about the sub-categories, categories and themes.

Trustworthiness of the data

To ensure the trustworthiness of the data, the findings were discussed in team meetings attended by researchers trained in conducting qualitative research. The group included two healthcare psychologists (DvdV and CB) and two healthcare scientists (BS and KP). DvdV and BS have completed academic training in qualitative research methods, and were supervised by KP. Furthermore, the analyses were performed by two researchers independently. Finally, team meetings consisted of in-depth discussions focused on establishing investigator triangulation and accounting for researcher bias.[34]

Results

Participants

A total of six caregivers of people with YOD were included in this study. Because one caregiver died between measurement points two and three, our final sample consisted of 17 interviews. The sample included five male spousal caregivers and one female spousal caregiver (Table 1). All of the YOD patients were female and had been diagnosed with Alzheimer's dementia or mixed dementia (i.e., Alzheimer's dementia and vascular dementia). The persons with YOD mean age at the time of diagnosis, mean age at the start of day care and mean age upon admission to a nursing home were 56.7, 58.2 and 60.8 years, respectively. Interviews with the sixth caregiver, i.e., interviews 15–17, yielded no new codes, which indicated that data saturation had been attained.[35]

Interviews

Through our analysis of the interviews, we identified six categories and 23 sub-categories (Table 2 and

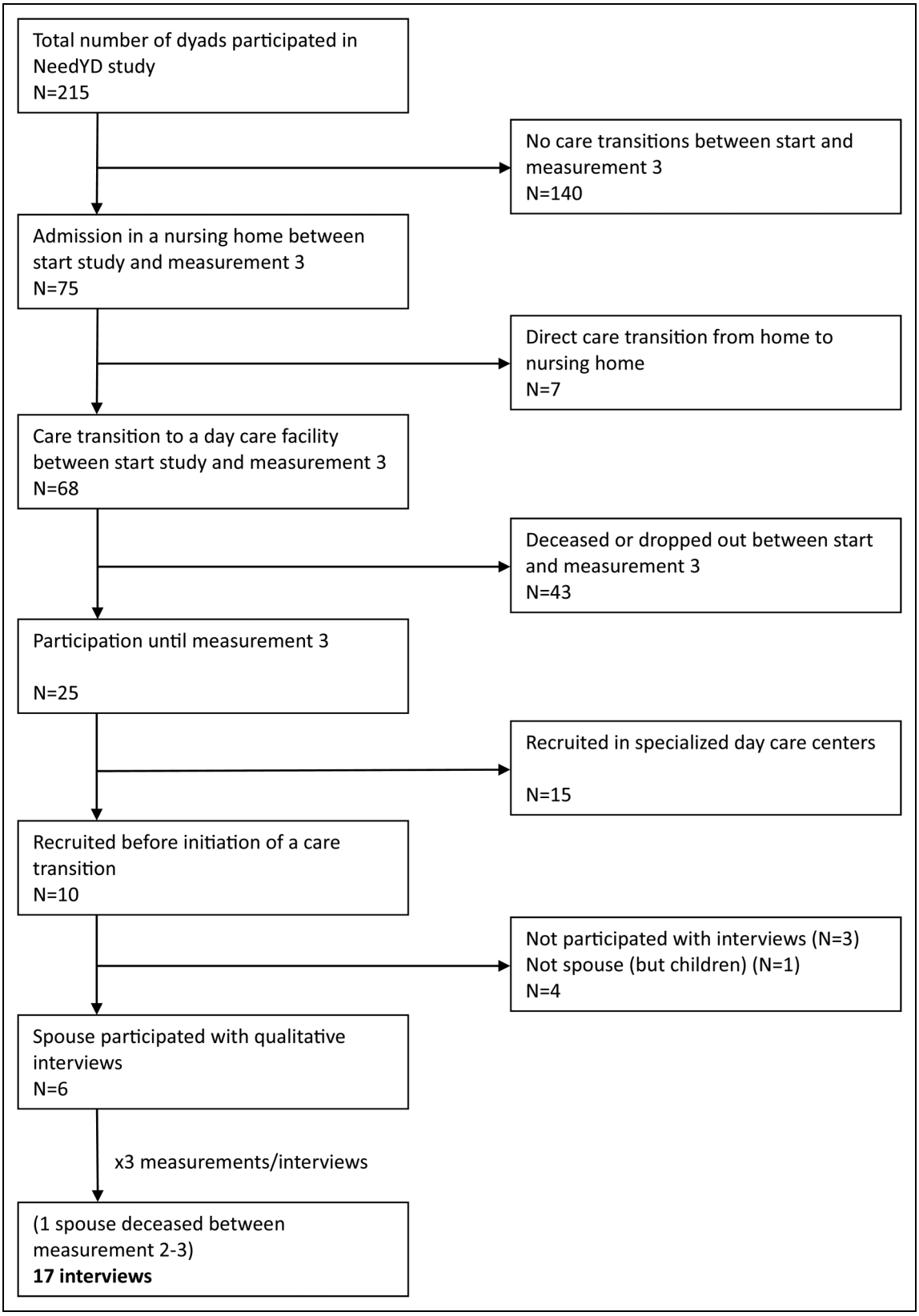

Figure 1. Flow chart of participant inclusion.

Table 1. Characteristics of the persons with YOD and their spouses.

Characteristic	Measure
Gender of the person with YOD, (males, females)	0, 6
Gender of the caregiver (males, females)	5, 1
Alzheimer's dementia diagnosis (N, %)	4 (66.7)
Mixed Alzheimer's/vascular dementia diagnosis (N, %)	2 (33.3)
Mean age at first symptoms (range)	53.0 (47–59)
Mean age at diagnosis (range)	56.7 (55–59)
Mean age at start of day care (range)	58.2 (55–60)
Mean age at admission to a long-term care facility (range)	60.8 (58–65)

Supplemental Material 3) influencing the decision-making process of initiating care transitions, which clustered around two analytically derived themes: an individual level and a contextual level. The individual-level theme consisted of four categories: (1) the character traits of the caregiver; (2) the caregiver's need for support; (3) impact on the relationship with the person with YOD; and (4) experienced burden. The contextual-level theme consisted of two categories: (1) the social environment and (2) the caregivers' experiences with healthcare professionals.

Theme 1: individual level

The first theme consisted of four categories concerning the caregivers themselves. The caregivers explained that they were increasingly responsible for the organization of care and support for their spouse. The decision to initiate care transitions was theirs to make.

Character traits of the caregiver

The first category consisted of the character traits of the caregiver. Caregivers expressed various ways in which they dealt with feelings of distress and the decision-making process. Caregivers expressed that they felt responsible for the health and well-being of the person with YOD. However, at the same time, they felt insecure because of uncertainties regarding the future. Caregivers also struggled with rational contemplations—for example, would starting day care or admitting their spouse to a long-term care facility be beneficial? They also discussed processing feelings of fear that such decisions would negatively affect their own health or the health of their loved one.

> "I also realized there would come a time I couldn't manage anymore. I knew it. But it's a question of rational thoughts and emotional feeling. Those are two different things. You can't just flip a switch."
>
> **- CG2.3 male, 58 years old**

Additionally, caregivers reflected on their own futures. These people were used to focusing on the needs of their loved ones rather than their own needs. However, caregivers were concerned about how to build a life of their own, especially after a care transition. In some cases, caregivers noted that they experienced a sense of indifference towards the caregiving trajectory; that situation inhibited their decision-making process. They explained their feelings by stating that indifference complicated their ability to think logically.

> "Now, I think of it [providing care] as a duty. That's it, nothing more."
>
> **- CG3.1 male, 58 years old**

Caregivers also reported less-helpful coping strategies such as denying the burden of caregiving. That situation sometimes resulted in the caregivers postponing other types of care and personal support that might have been beneficial to their own mental health. Some caregivers perceived in hindsight that they downplayed the increasing cognitive decline of their loved one. Doing so might have resulted in the social environment perceiving situations to be less distressing than they truly were. In turn, that situation might have exacerbated the caregiver's sense of isolation in the caregiving role.

Caregivers also noted supporting factors, such as having enough mental space to think, in the decision-making process around care transitions. They felt that having enough space to think allowed them to maintain control of the situation and keep an eye on the challenges that might arise in the future. Furthermore, caregivers noted that opportunities to distract themselves from daily concerns, including employment, were helpful in staying positive and accepting the increasing care needs of their spouses.

> "I find satisfaction in my job… Next to the salary I receive, there is also a reward in the appreciation I feel."
>
> **- CG2.1 male, 66 years old**

Caregiver support needs

The second category pertained the caregivers' support needs. Caregivers noted the need to improve their well-being and their desire to let the person with dementia live at home for as long as possible as being among the most important aspects of their decision-making process. Caregivers had clear beliefs about care transitions and the circumstances under which such transitions should be initiated. They expressed that it was important to have personal limits in terms of caregiving. Some caregivers expressed that helping their loved one with their toilet-related needs crossed a line. Other caregivers experienced that a grieving process took place in tandem with the

Table 2. Overview of the two themes, six categories and 23 sub-categories.

Individual level	Contextual level
Character traits of the caregiver	*Social environment*
Coping styles	Support received by the caregiver from their social environment
Sense of control	Interactions within the household
Future prospects on a personal level	Interactions with the social environment
Caregiver support needs	*Experiences with healthcare professionals*
Explicit current support needs	Healthcare professionals at home
Desire to provide care at home as long as possible	Healthcare professionals at day care
Providing care no longer feasible at home	Healthcare professionals at a nursing home
Previous experiences with YOD care provision	
Specialized YOD services needed	
Range of experiences with YOD services	
Care transitions considerations	
Impact on quality of the relationship with the person with YOD	
Needs of the person with YOD	
Changes in relationship roles	
Experienced burden	
Experienced burden of YOD symptoms	
Impact of dementia symptoms on caregiving burden	
Impact of behavioral problem management	
Course of dementia	
Nursing home admission considerations	

YOD: young-onset dementia. A complete overview of all of the codes on a sub-category basis appears in Supplemental Material 3.

caregiving trajectory; they described the course of gradually losing their spouse as a dramatic life event. Good mental health was beneficial for avoiding situations in which crisis interventions were required, the caregivers noted. They also highlighted that the decision-making process was facilitated when they were able to reflect on early experiences and the resulting implications. Such reflections often arose shortly after new situations emerged (i.e., following meetings with peers in support groups or after a guided tour of a nursing home). Those reflections in turn led the caregivers to have new valuable insights into their present and future support needs. Caregivers also noted that timely initiation of care was important because there was a perceived decrease in social support while support needs increased. Caregivers felt increasingly on their own and noted that their social circles did not understand their situation. As their role became more challenging, the caregivers were increasingly conscious of their need for support.

> "They say that during this time you get to know your real friends. And it's really true. That's what I find really hard as this is when you need them the most."
>
> **- CG6.3 male, 59 years old**

Professional healthcare services paid scant attention to caregivers' underlying needs, and the process of obtaining professional care was complex and time-consuming, caregivers noted. Negative experiences in which caregivers felt that their support needs were unmet, sometimes in the context of healthcare professionals, further hindered the initiation of care transitions. Those negative experiences included limited efforts made by healthcare professionals and insufficient levels of communication and coordination of care. Furthermore, caregivers expressed concerns about the amount and availability of YOD-specialized services. Those concerns were particularly pronounced when the caregivers' children still lived at home.

> "They say there are older people everywhere, everywhere you look [within a regular care facility]. There are not a lot of young people."
>
> **- CG5.2 female, 66 years old**

The availability of intermittent stays at long-term care facilities and flexible options to extend day care helped to provide respite care to the caregivers. The willingness of the person with YOD to accept the care and whether that care actually led to a reduction in the caregiver's burden were considered important prerequisites to continuing the use of specific types of care and support. In those cases, care transitions were considered beneficial. Caregivers in those situations experienced positive communication with healthcare professionals. Furthermore, caregivers felt supported and were better able to make decisions about the initiation of care when they participated in peer-support groups. Participation in such groups revealed that other people were having similar experiences (for instance,

regarding dealing with loss and grief) and also yielded practical tips for the management of changing behavior.

Impacts on relationships with YOD patients

The third aspect concerned the impacts on the relationship with the person with YOD. Changes in the perceived relationship with the person with YOD influenced the ways in which caregivers perceived the necessity of care transitions. Caregivers felt a loss of intimacy, a loss of the relationship itself, a lack of reciprocity and role changes; specifically a transition from partner to caregiver. The loss in relationship quality was linked to the increasingly unmet needs of the person with YOD, which sometimes resulted in hastened initiation of care transitions.

> "I am happy she goes to the day care. She asks me questions, all day long. All I do is provide care. I used to have time to read the paper in between, but now I can't do anything for myself when she is at home."
>
> **- CG5.2 female, 66 years old**

On the other hand, caregivers postponed care transitions when their relationship was strong or when they felt they were getting closer to their loved ones.

> "Our relationship is stronger than ever. We can't talk to each other, but we hug all the time."
>
> **- CG4.2 male, 60 years old**

Caregivers noted that they constantly had to adapt to new situations and that they felt responsible for being in charge of meeting the needs of their spouse. Those needs included, for example, staying active and looking presentable. Moreover, caregivers processed these changes in the relationship as losing a part of themselves.

> "The relationship is gone. She's still here, but I am alone. It is difficult, but that's just how it is."
>
> **- CG6.1 male, 57 years old**

When caregivers were able to maintain the physical and mental health of their spouse, they were better able to engage in their role as caregiver. Some caregivers tried to stay active together with their spouse, which improved their own health as well. Furthermore, they described that dementia had brought them closer together since they felt they needed each other more than ever.

Experienced burden

The last category on the individual level regarded the burden experienced by the caregivers. Caregivers felt obliged to organize all the care and support since they had married 'for better and for worse.' Additionally, some of the caregivers experienced putting their own life on hold. Together with the increasing care needs of their spouse, this situation resulted in an increase in perceived burden.

> "Your social life gets quite limited or barely exists because you are so busy with your wife during the week, and the weekends. And well, always."
>
> **- CG6.2 male, 58 years old**

Caregiver burden increased even more when caregivers had to adapt their physical environment and their interactions with the person with YOD. For example, telling white lies to comfort the person with YOD made caregivers feel guilty. Some caregivers expressed a gradual loss of their counterpart as their spouse became increasingly reliant on them. During this process, caregivers also experienced a shift in the type of decisions they made for their loved one. Those decisions ranged from small decisions in daily life to life-changing decisions (e.g., the initiation of care transitions). Caregivers noted that their responsibility to improve the quality of life of their loved one weighed heavily on their shoulders.

> "At the time I found it really difficult [the start of day care]. It felt, like when you drop your child off at school, that you would hand over care to someone else. That was difficult for me."
>
> **- CG4.2 male, 60 years old**

Grieving was described as a lengthy and painful process that consisted of several landmarks. Those landmarks included the moment of diagnosis, the loss of a relationship and the actual death of the person with YOD. The decision-making process concerning admission to a long-term care facility was also noted as a landmark of grieving; it was the moment in which a beloved one was let go. The burden experienced by such grief led to emotions such as anxiety and frustration, which hindered caregivers in reflecting objectively about the caregiving trajectory and deciding whether care transitions were necessary. Changes in the spouse's behaviors and emotional and cognitive functioning also influenced the caregivers' experienced burden. For instance, higher levels of memory impairment resulted in the person with YOD becoming frustrated and even aggressive; those states increased caregiver distress. Nevertheless, caregivers felt that admitting their loved one to a long-term care facility was a form of abandonment.

On the other hand, some caregivers noted that they had learned to focus on positive aspects and the new competencies they had acquired during their role as caregiver. Individuals who developed organizational and social skills

expressed they could handle higher levels of burden, which supported their decisions to postpone care transitions.

> "By taking all the work out of her hands. (…) I think I learned from it. I let her chug along and patience, patience, patience. I surprised myself. I wasn't such a patient guy before."
>
> **- CG2.1 male, 66 years old**

Hindering convictions could turn into helpful beliefs when caregivers experienced that care transitions actually helped to improve the quality of life of their spouse with YOD.

Theme 2: contextual level

The second theme reflected the ways in which caregivers felt supported or hindered by situations they had little control over.

Social environment

The first aspect on the contextual level pertained to the social environment. Family members, friends and acquaintances were noted to be important contextual aspects. Both the quality and quantity of the experienced support provided by the social environment influenced the initiation of care transitions. In many occasions, caregivers described a decrease in relationship quality in their social environment and a decrease in the number of visits from family and support from friends. An often-heard explanation was that family members and acquaintances experienced difficulties dealing with behavioral changes. The corresponding increase in social isolation led caregivers to believe that they were on their own.

> "It is also clear that friends and acquaintances visit us less. Really a lot less. I would say if everything is normal you have friends. Maybe two hands full, maybe more. If you look two years forward, you can count them on one hand."
>
> **- CG6.3 male, 59 years old**

A lack of support in some cases triggered the initiation of care transitions, because these caregivers could no longer combine their role as caregiver with maintaining their household and/or job responsibilities.

On the other hand, some caregivers experienced better relationships with their family members, friends or acquaintances, because they felt understood and content in the fact that the complexity of their caregiving situation was acknowledged. In addition, the caregivers expressed improved relationships with their social circles because their friends were showing empathy for their role as caregiver. Some of the caregivers noted that either acquaintances or neighbors increasingly supported then when family members failed to do so; the converse was also true.

> "A lot of people don't know what to do or how to react. And then they come and visit her. Maybe I'm being disrespectful, but then they've seen her and they never come again."
>
> **- CG1.3 male, 61 years old**

Experiences with healthcare professionals

The decision-making process was also influenced by healthcare professionals and the caregivers' perceived experiences with those professionals. First impressions of healthcare professionals were often disappointing or frustrating experiences, according to the caregivers. They described situations in which healthcare professionals gave them insufficient, incorrect or contradictory information about YOD. Furthermore, caregivers noted that they had to deal with difficulties finding and accessing YOD-specialized services. The perceived bureaucracy in healthcare organizations, difficulties initiating care transitions and the paucity of YOD-specialized services were all noted as barriers in the caregiving trajectory. Caregivers required specialized services close to home, and some caregivers expressed that they thought they were better off without such services.

> "No, I received very little information there and I already mentioned that at the time. It was really very little information. But oh well. A lot of things we resolved ourselves anyway."
>
> **- CG3.1 male, 58 years old**

General practitioners, case managers and social workers were noted as being important healthcare professionals, particularly when they provided useful information in tandem. Caregivers required information about the course of dementia and the bureaucratic procedures concerning care transitions. Additionally, receiving empathetic reactions from healthcare professions about the caregiver's burden helped to change their convictions of being better off alone. Participating in caregiver support groups also helped to make caregivers feel more in control.

> "You get more from your GP, and by coincidence we have a really good one. The best is we have a case manager. That's it! She's already coming for four years, I think. In the beginning for my wife, she was her client. But now she comes for me. She helps to fill the gaps and I can always call her or mail her. She supports me!"
>
> **- CG5.2 female, 66 years old**

Caregivers felt supported in their decision to initiate a care transition when they explicitly experienced a beneficial effect shortly thereafter. For instance, sometimes people

with YOD experience feelings of being understood and having peers at a daycare center. Some caregivers noted these experiences and contrasted them with previously held beliefs that day care is a service that consists of age-inappropriate activities.

> "If I didn't have the support group [with fellow caregivers], then I wouldn't have had a lot of information. (…) We started six years ago and we still have contact. I feel really supported!"
>
> **- CG5.1 male, 65 years old**

Caregivers were most resistant to admitting their loved one to a nursing home. This situation was often exacerbated by their initial experiences with nursing home admission. They felt that healthcare professionals were unable to provide the same quality of care as they provided themselves; that mindset persisted most strongly during the first few weeks after admission. For example, some caregivers noted that people with YOD were being treated as numbers, rather than people, by nursing home staff. Those caregivers did not feel that their burden was being relieved, at least not during the first few weeks of admission.

> "These are people, not animals. And even animals deserve decent care. And these are people, they deserve even better care. Treat them like your brother or sister, mother or father."
>
> **- CG3.3 male, 60 years old**

After two or three months, most caregivers perceived that the level of competence of formal caregivers increased; they accordingly decided to collaborate more with the professionals. Two explanations were primarily responsible for that shift in mindset. First, caregivers perceived that healthcare professionals were increasingly aware of the needs of the person with YOD. Second, there was improved communication between the caregiver and the professionals.

Discussion

To the best of our knowledge, this investigation is the first qualitative study to focus on the lived experiences of caregivers of people living with YOD regarding care transitions in the post-diagnostic period. The narratives that we uncovered revealed two themes, six categories, and 23 subcategories related to the decision-making process regarding care transitions. The first theme, the individual level of the caregivers, consisted of the character traits of the caregiver, the caregiver's need for support, the impact on the relationship with the person with YOD, and experienced burden. The second theme concerned contextual aspects that influenced the decision-making process regarding care transitions. That contextual level included both the social environment and previous experiences with healthcare professionals. Interconnections among the categories revealed three overarching perspectives on the decision-making process. These perspectives captured shifts in caregivers' cognitive processes, the influence of caregivers' character traits on the perceived burden, and the impact of contextual factors on caregiving experiences.

The first perspective that we gained concerned the impact of dementia on the shift in caregivers' cognitive processes due to changes in the relationships quality with their loved ones and the experienced burden. Caregivers experienced a loss of reciprocity in their relationships and found it difficult to deal with changes in their caregiving situations. The inability to express their thoughts and the impact of caregiving with loved ones appeared to be associated with feelings of guilt. While caregivers experienced increasing responsibilities, they also experienced more feelings of grief, which could have impaired cognitive appraisal in decision-making. Such developments in the cognitive processes were considered to be barriers to the decision-making process regarding care transitions. These findings are consistent with those of previous studies linking caregiver burden with reduced quality of life and higher levels of distress, anxiety and depression.[14,15] Furthermore, changes in relationship quality have been frequently noted in the literature and are hypothesized to be subject to continuous redefinition,[19,20] a process that can be profoundly impacted by grief, which is known to negatively influence cognitive processes throughout the entire caregiving trajectory. It has been shown that YOD caregivers encounter three phases of grief in the disease process: obtaining the diagnosis, losing their spouse during the progression of dementia, and their spouse's actual death.[17]

Some caregivers in our study reported a reduced sense of caregiving strain when they perceived that dementia actually had, paradoxically, strengthened their emotional bond with their loved one. Those caregivers appeared more reflective about how they had learned to approach caregiving challenges and demonstrated greater adaptability to changes within the caregiving context. The feeling of being closer to one another and the ability to adapt to changes were considered to be facilitators in the decision-making process. A possible explanation for this may be the concept of resilience. Flexibility, positive cognitions, self-efficacy, social support, and spirituality are considered key attributes of resilience.[36] Adopting a resilience perspective is useful in the context of YOD, as it may help explain why some caregivers continue to function well despite challenging circumstances. Support or interventions aimed at strengthening these attributes may help optimize caregiver well-being.[36] Notably, in our study caregivers mentioned all of these attributes except for spirituality. Previous research has shown that YOD caregivers wish to delay institutionalization for as long as possible,[23] which is consistent with our results. These findings are important and relevant, because the goals of YOD caregivers—in this case,

delaying institutionalization—are often in line with those of their spouse.[21]

The second perspective found in this study concerned a discrepancy between the actual experienced caregiver strain and their perception of that burden. Caregivers expressed ambivalence about the necessity of care transitions, acknowledging at the same time that such transitions could adversely affect their loved one's wellbeing. This underlying dichotomy likely constrained caregivers' decision-making by making it more difficult to reconcile emotional and practical considerations. This tendency appeared strongest among caregivers who engaged in less adaptive coping strategies (e.g., denial of dementia progression or minimization of personal strain). Such caregivers might have received inadequate support from their social circles accordingly, considering their limited awareness of the situation and the consequent postponement of appropriate care and support. These processes have been described in the literature as the early-stage needs paradox; caregivers have indicated in hindsight that initiating care transitions earlier in the caregiving trajectory would have been beneficial and might have aided in postponing admission to a nursing home.[26] Moreover, evidence from the literature indicates that caregivers could benefit from adaptive coping strategies, including acceptance of their loved one's changing abilities and the use of humor to navigate shifting caregiving situations.[16] Conversely, we found that some caregivers had sufficient cognitive or reflective space, which was associated with a greater perceived sense of control. Those caregivers generally adopted more adaptive coping styles. It is likely that the use of more adaptive coping styles results in a better communication with one's social environment and aids in maintaining a forward-looking view of the caregiving trajectory. Those caregivers accordingly appeared better poised to initiate care and support and set in motion care transitions that addressed the needs of their spouse.

We also found that previous experiences with others, such as family members, friends or healthcare professionals, influenced the decision-making process. Caregivers that we studied often experienced that social support diminished over time, which might be explained by the aforementioned lack of acknowledgement of the dementia and recognition of symptoms by their social circles. Moreover, caregivers expressed various difficulties regarding organizing formal care with healthcare professionals. Studies regarding the support and practical aspects of YOD services have shown that caregivers often receive lower levels of social support and specialized services are often limited, poorly integrated into the healthcare system and additionally characterized by bureaucracy.[18,37] That combination, in tandem with decreased social support, hindered the caregivers' decision-making process.

On the other hand, we found that caregivers emphasized the benefits of social support such as peer-support groups. Such support was believed to facilitate the decision-making process. This was especially beneficial when those caregivers noted positive experiences with healthcare professionals, such as the feeling of being recognized by them. This finding is consistent with previous research that reported the beneficial effects of social support[13] and an understanding of healthcare professionals[21] on caregivers' quality of life.

Strengths and limitations

Our use of investigator triangulation was a strength; this technique improved the trustworthiness of the data by minimizing the risk of researcher bias. And although purposeful sampling was used to capture dyads who had gone through several care transitions, this approach may have led to selection bias. It is possible that we omitted caregivers with other unique experiences or perspectives. For instance, caregivers of people with YOD who were admitted to a long-term care facility without initiating than a day care facility might have been able to speak about additional barriers related to rapid care transitions. On the other hand, caregivers of people with YOD who still lived at home after two years might have experienced other facilitators regarding the care and support that they received. Another limitation concerns the generalizability of our results. In our sample, all of the people with YOD were female, and the majority of the caregivers were male, making gender-related influences on the findings likely. Furthermore, all interviews were conducted by female research assistants, which may have influenced participants' responses through interviewer-related or social desirability bias. A further limitation is that all of the people with YOD had been diagnosed with Alzheimer's disease or mixed dementia. Young-onset dementia is caused by a wide variety of etiologies.[1] Those varying etiologies result in different needs for both the person living with YOD and their caregiver. Given the qualitative and context-dependent nature of this study, the transferability of the findings to other healthcare contexts should be considered with caution. Differences in healthcare organization, availability of specialized YOD services, and access to support may influence caregivers' experiences and the decision-making process surrounding care transitions.

Recommendations and conclusions

Future caregivers, and people diagnosed with YOD as well, can benefit from the lessons learned from this study. This study reconfirms the pressing need for early diagnosis of YOD and for optimizing the provision of relevant information and support throughout the post-diagnostic trajectory.

The caregivers in our study demonstrated a dynamic process of stress, in which stress arose from multiple

stressors to which they were exposed. This is consistent with the stress process model,[38] which likewise conceptualizes stress as shaped by various primary and secondary stressors and highlights opportunities for intervention targeting these stressors and strengthening social support to temper adverse outcomes. Translating these insights from our study to daily practice suggests that improving the availability of accessible caregiver peer-support groups may help to reduce caregivers' risk of social isolation and facilitating the strengthening of resilience. Other factors that contribute to enhancing resilience include promoting positive cognitions, which can coexist with negative emotions related to psychosocial consequences of YOD, fostering self-efficacy and resourcefulness, and providing social support.[36] Furthermore, predicting and coordinating the need for care transitions could be more effective if caregiver burden is mapped periodically. Such work could be done, for instance, by a case manager or social worker. Implementing this would provide healthcare professionals with insight into the complex interplay between caregivers' sense of control and their vulnerability. Over and above this, improving communication and collaboration between ad-hoc caregivers and healthcare professionals might aid in supporting caregivers. Acknowledgement and recognition of grieving processes can also support caregivers in their decision-making process related to care transitions. Healthcare professionals should also be aware of the early-needs paradox.[26] Such awareness might aid in the organization of advance care planning related to care transitions. This planning is paramount for both caregivers and people with YOD senses of control.

Future research should focus on designing interventions to improve the availability and accessibility of peer-support groups, implement systematic monitoring of caregiver burden, and enhance the support provided by healthcare professionals to caregivers. Furthermore, future studies could explore whether caregiver characteristics, such as sex, influence experiences of care transitions and caregiving challenges.

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Ethical considerations

The protocol of the NeedYD study was approved by the Medical Ethics Committee of Maastricht University Medical Center, the Netherlands (MEC 07-2-38) and includes the approval for future use, with due consideration of GDPR legislation. This study adheres to the principles stated in the 'Declaration of Helsinki'.

Consent to participate

All participants provided written informed consent prior to participation.

Consent for publication

Not applicable.

Author contribution(s)

Dennis van de Veen: Conceptualization; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft.
Bo Smeets: Formal analysis; Writing – original draft.
Kirsten Peetoom: Methodology; Supervision; Writing – review & editing.
Marjolein de Vugt: Conceptualization; Supervision; Writing – review & editing.
Christian Bakker: Conceptualization; Funding acquisition; Methodology; Project administration; Supervision; Writing – review & editing.
Raymond Koopmans: Conceptualization; Funding acquisition; Supervision; Writing – review & editing.

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Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability statement

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

Supplemental material

Supplemental material for this article is available online.

References

1. van de Veen D, Bakker C, Peetoom K, et al. Provisional consensus on the nomenclature and operational definition of dementia at a young age, a Delphi study. *Int J Geriatr Psychiatry* 2022; 37: 10.1002/gps.5691.
2. Hendriks S, Peetoom K, Bakker C, et al. Global prevalence of young-onset dementia: a systematic review and meta-analysis. *Jama Neurol* 2021; 78: 1080–1090.

3. Hendriks S, Peetoom K, Bakker C, et al. Global incidence of young-onset dementia: a systematic review and meta-analysis. *Alzheimers Dement* 2023; 19: 831–843.
4. van Vliet D, de Vugt ME, Bakker C, et al. Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychol Med* 2013; 43: 423–432.
5. Mendez MF. Early-onset Alzheimer disease and its variants. *Continuum (Minneap Minn)* 2019; 25: 34–51.
6. Draper B, Cations M, White F, et al. Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study. *Int J Geriatr Psychiatry* 2016; 31: 1217–1224.
7. Kvello-Alme M, Brathen G, White LR, et al. Time to diagnosis in young onset Alzheimer's disease: a population-based study from central Norway. *J Alzheimers Dis* 2021; 82: 965–974.
8. van Gils AM, Rhodius-Meester HFM, Leeuwis AE, et al. Young-onset dementia in memory clinics in the Netherlands: study design and description of PRECODE-GP. *Alzheimers Dement (Amst)* 2023; 15: e12471.
9. Bodde HE, Poos JM, Kolman G, et al. The prevalence and incidence of young onset dementia in The Netherlands: a prospective study in two catchment areas. *Alzheimers Res Ther* 2026; 18: 200.
10. Giebel C. Young-onset dementia and its difficulties in diagnosis and care. *Int Psychogeriatr* 2022; 34: 315–317.
11. Bayly M, O'Connell ME, Kortzman A, et al. Family carers' narratives of the financial consequences of young onset dementia. *Dementia (London)* 2021; 20: 2708–2724.
12. Carter JE, Oyebode JR and Koopmans R. Young-onset dementia and the need for specialist care: a national and international perspective. *Aging Ment Health* 2018; 22: 468–473.
13. Bannon SM, Reichman M, Popok P, et al. Psychosocial stressors and adaptive coping strategies in couples after a diagnosis of young-onset dementia. *Gerontologist* 2022; 62: 262–275.
14. Spreadbury JH and Kipps CM. Measuring younger onset dementia: a comprehensive literature search of the quantitative psychosocial research. *Dementia (London)* 2019; 18: 135–156.
15. Dixit D, Spreadbury J, Orlando R, et al. Quality of life assessments in individuals with young-onset dementia and their caregivers. *J Geriatr Psychiatry Neurol* 2021; 34: 426–433.
16. Bannon S, Reichman M, Popok P, et al. 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: e123–e139.
17. Wiggins M, McEwen A and Sexton A. Young-onset dementia: a systematic review of the psychological and social impact on relatives. *Patient Educ Couns* 2023; 107: 107585.
18. Spreadbury JH and Kipps C. Measuring younger onset dementia: what the qualitative literature reveals about the 'lived experience' for patients and caregivers. *Dementia (London)* 2019; 18: 579–598.
19. Holdsworth K and McCabe M. The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: a systematic review. *Int Psychogeriatr* 2018; 30: 15–29.
20. Bruinsma J, Peetoom K, Millenaar J, et al. The quality of the relationship perceived by spouses of people with young-onset dementia. *Int Psychogeriatr* 2024; 36: 482–491.
21. Bannon SM, Reichman MR, Wang K, et al. A qualitative meta-synthesis of common and unique preferences for supportive services among persons with young onset dementia and their caregivers. *Dementia (London)* 2022; 21: 519–539.
22. Ray CA, Ingram V and Cohen-Mansfield J. Systematic review of planned care transitions for persons with dementia. *Neurodegener Dis Manag* 2015; 5: 317–331.
23. Bakker C, de Vugt ME, van Vliet D, et al. The use of formal and informal care in early onset dementia: results from the NeedYD study. *Am J Geriatr Psychiatry* 2013; 21: 37–45.
24. Cations M, Loi SM, Draper B, et al. A call to action for the improved identification, diagnosis, treatment and care of people with young onset dementia. *Aust N Z J Psychiatry* 2021; 55: 837–840.
25. Stamou V, La Fontaine J, Gage H, et al. Services for people with young onset dementia: the 'Angela' project national UK survey of service use and satisfaction. *Int J Geriatr Psychiatry* 2021; 36: 411–422.
26. Boots LM, Wolfs CA, Verhey FR, et al. Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *Int Psychogeriatr* 2015; 27: 927–936.
27. Sampson EL, Anderson JE, Candy B, et al. Empowering better end-of-life dementia care (EMBED-care): a mixed methods protocol to achieve integrated person-centred care across settings. *Int J Geriatr Psychiatry* 2020; 35: 820–832.
28. Tong A, Sainsbury P and 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: 349–357.
29. van Vliet D, Bakker C, Koopmans RT, et al. Research protocol of the NeedYD-study (needs in young onset Dementia): a prospective cohort study on the needs and course of early onset dementia. *BMC Geriatr* 2010; 10: 13.
30. Creswell JW and Creswell JD. *Research design. Fifth edition ed*. Sage Publications, Inc., 2018.
31. Elo S and Kyngas H. The qualitative content analysis process. *J Adv Nurs* 2008; 62: 107–115.
32. Muhr T. *ATLAS.ti. 5.0 ed*. Scientific Software Development GmbH, 2004.
33. Pope C, Ziebland S and Mays N. Qualitative research in health care. Analysing qualitative data. *Br Med J* 2000; 320: 114–116.
34. Carter N, Bryant-Lukosius D, DiCenso A, et al. The use of triangulation in qualitative research. *Oncol Nurs Forum* 2014; 41: 545–547.
35. Guest G, Bunce A and Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Method* 2006; 18: 59–82.

36. Kobiske KR and Bekhet AK. Resilience in caregivers of partners with young onset dementia: a concept analysis. *Issues Ment Health Nurs* 2018; 39: 411–419.
37. Cations M, Withall A, Horsfall R, et al. Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. *PLoS One* 2017; 12: e0180935.
38. Pearlin LI, Mullan JT, Semple SJ, et al. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990; 30: 583–594.