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## Living with young-onset dementia in the family – a mixed method study

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### ABSTRACT

**Background:** Studies on disease-related obstructions experienced in everyday life of younger people with dementia (YOD ≤ 65 years) and their families are encouraged.

**Aim:** To explore how the family carers experience six predefined topics that influence the everyday life and needs of persons with YOD.

**Method:** A quantitative and a qualitative study including family carers of persons with young-onset Alzheimer's dementia (AD) and frontotemporal dementia (FTD). Seventy-four informants responded to the Camberwell Assessment of Needs in the Elderly (CANE) and individual interviews were conducted with 13 informants.

**Results:** Family carers of persons with YOD reported few unmet needs in the CANE assessment. Needs related to behavior and close relationships were reported significantly more frequent ( $p < 0.1$ ) in persons with FTD than in persons with AD. From the qualitative data, six main themes were emphasized: daily activities turned upside down, involuntary loss of previous social network, losing close relationship, but maintaining a friendship with the spouse, unpredictable behavior adds burdens to a changing life, health and life risks, and economic insecurity for future life and caring costs.

**Conclusion:** Whilst family carers quantitatively reported unmet needs, the individual interviews reported several major difficulties in everyday life.

### ARTICLE HISTORY

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### KEYWORDS

Alzheimer's dementia; communication; coping; demands; early-onset dementia; frontotemporal dementia; triangulation

## Introduction

Young-onset dementia (YOD) is characterized by symptom debut before the age of 65 years. The prevalence of YOD in Norway, a country with a population of 5.5 million people, is estimated to be less than 5000 (Ikejima et al., 2009; Zhu et al., 2015). However, a recent Norwegian population based study found the prevalence of YOD to be 143.1 per 100,000 persons at risk in the age group of 45–64 years (Kvello-Alme et al., 2019). Two of the most common types of dementia in early life are Alzheimer's disease (AD) and frontotemporal dementia (FTD) (Engedal & Laks, 2017, p. 33). All types of dementia are progressive, leading to increasing impairment in daily living activities and requires the need of assistance (Coyle-Gilchrist et al., 2016; Ratnavalli et al., 2002; Rosness et al., 2016). The presentation of rare conditions and atypical symptoms contribute to a longer delay before a correct diagnosis is made compared to dementia disorders that debut after 65 years (late-onset dementia) (Rosness et al., 2008; van Vliet et al., 2013). Given the non-normative age of onset, not only is the diagnosed person profoundly affected by this life-changing and life-shortening illness, so is the entire family (Aslett et al., 2019; Chirico et al., 2022; Johannessen et al., 2016a; Larochette et al., 2020).

YOD creates challenges that differ from those presented in persons with late-onset dementia due to the inherent differences between the age cohorts. Fundamental differences, apart from age, include physical fitness and the stage of life in

which people establish their own family and secure a career to provide for their future. Many people with YOD are thus at the peak of their productive years, with children still living at home and an active lifestyle that may be hazardous to the physical safety of themselves or others (Johannessen et al., 2016a). Younger people tend to have broader social networks and more obligations compared to older people, including care obligations for an aging parental generation (Brenna, 2021; Ducharme et al., 2013).

As dementia progresses, the spouse or adult children must compensate for difficulties in fulfilling roles and responsibilities for their family members (Wong et al., 2020). The dynamics within the family are gradually shifting, until eventually, the roles and responsibilities are all re-defined (Egilstrod et al., 2019; Gelman & Rhames, 2020; Holdsworth & McCabe, 2018; Johannessen et al., 2016a). The available services for persons with YOD are highly limited and often non-specialized; therefore, they are used reluctantly or not at all. Most families prefer to provide care at home for as long as possible. The support and health services provided to persons with YOD living at home, as perceived by the persons themselves and/or their family carers, are essential to ensure and secure the activities of everyday life (Johannessen et al., 2016a, 2016b).

Both persons with YOD and their families need more information about the disorder, as well as tailored care services (Karnatz et al., 2021; Tookey et al., 2021). Earlier research has pointed out six topics related to problems and needs in everyday

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\*These authors shared first authorship

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life arising from YOD where future research is warranted. These topics include a lack of daily activities, loss of friendship, and feelings of social isolation and exclusion for persons with YOD, as well as a loss of intimacy and poorer romantic relationships (Bakker et al., 2014; Chow et al., 2016; Holdsworth & McCabe, 2018). Furthermore, behavioral and personality changes in the persons with YOD, which increase relational problems, are highly challenging for the family (Arai et al., 2007; Bakker et al., 2014; Ducharme et al., 2013; Millenaar et al., 2016). Reduced levels of functioning lead to issues of risk and danger, which (Beattie et al., 2004; Millenaar et al., 2016; Wawrziczny et al., 2016) also pose a challenge for the person with YOD and their family, along with work related and financial consequences due to the disease, including early retirement for the person with YOD and their carers (Chow et al., 2016; Johannessen et al., 2017; Kimura et al., 2015; Luscombe et al., 1998; van Vliet et al., 2010). To explore these topics, studies with a combined quantitative and qualitative approach have been encouraged (Bressan et al., 2020). In this study, we therefore assess these six predefined topics (daily activities, social network, close relationships, behavioral changes, safety, and economy) using multiple perspectives to enhance and enrich the understanding of how the family carers experience the everyday life and needs of persons with YOD. We expect the quantitative and qualitative approach to be of equal importance for the development of this understanding.

## Aim

To explore how the family carers experience six predefined topics that influence the everyday life and needs of persons with YOD.

## Method

Two data sources of equal importance, quantitative and qualitative, were applied and combined. Thus, the method has a mixed explanatory concurrent method design (Polit & Beck, 2017, p. 585). This is a one phase design where both quantitative and qualitative data were collected and analyzed, thereafter results from the separate analysis of quantitative and qualitative data are combined in the discussion section. The data collection took place from 2014–2017, while the analyses of the materials took place in 2022. The data collection and the analysis of quantitative and qualitative data were performed independently by each other.

### The quantitative data source

#### Informants

Family carers of persons with YOD from five memory clinics in Norway, as previously described, were invited to partake in the

quantitative part of the study (Hvidsten et al., 2018). The criterion for participation was being the main family carer or a significant other of a person with YOD. In total, 74 Norwegian family carers, spouses, or adult children of persons with young-onset AD ( $n=50$ ) or FTD ( $n=24$ ) participated in the study. The initial YOD diagnosis was received from zero to eight years before the CANE assessments were made (mean 2.0 years). The assessments were carried out at the local memory clinics or in the families' homes. Further characteristics are given in Table 1.

#### Assessment

The inventory of the Camberwell Assessment of Needs in the Elderly (CANE) (Reynolds et al., 2000), which consists of 24 items, was used to assess the needs of the persons with YOD in semi-structured interviews. For the present study, we used the following items: (1) Daily activities, (2) Social network, (3) Close relationships, (4) Behavior, (5) Safety, and (6) Economy. The family carers reported these needs as experienced from the family carers' perspectives. The scale for rating the needs is: 0 = No need, 1 = Met need, 2 = Unmet need, 3 = Unknown. As an example, the explanatory text to the topic of close relationships is: Does the person have a spouse, relative, or friend with whom they have a close emotional/physical relationship? 0 = No need (happy with current relationships or does not want any relationships), 1 = Met need (has problems concerning relationships, specific plans, counseling, helpful advice/support, internet dating/online friendships), 2 = Unmet need (socially isolated, lonely. Lack of close confidant or trusting relationship).

### The qualitative data source

#### Informants

Thirteen family carers of persons with YOD were asked to participate in a qualitative individual interview by two project nurses. The informants comprised five wives, five husbands, and three daughters, aged between 36 and 73 years (Table 2). Twelve of the persons with YOD were diagnosed with AD, and one of them with FTD, and they were between 60 and 70 years old at the time the interviews were conducted. All these informants participated in the quantitative part of the project and were informed about their spouses' or parents' diagnosis by a psychiatrist or geriatrician at a memory clinic. The severity of dementia ranged from mild to severe. The symptoms of dementia had been present at least six months before they were diagnosed, and the initial YOD diagnosis was received from 1 to 9 years before the interview (mean 4.7 years).

#### The qualitative interviews

A convenient place for each informant to do the interview was chosen (Berg & Lune, 2012, p. 137; Kvale & Brinkmann, 2009, p.

**Table 1.** Characteristics of the carers and the persons with young-onset dementia (YOD) in the quantitative part of the study.

Carer		Person with YOD	
<i>N</i> = 74		<i>N</i> = 74	
Age, yrs mean (SD)	57.1 (11.7)	Age, yrs mean (SD)	63.8 (4.7)
Sex, n (%)	44 (59.5)	Sex, n (%)	35 (47.3)
• Female	30 (40.5)	• Female	39 (52.7)
• Male		• Male	
Relationship, n (%)	51 (68.9)	Diagnosis, n (%)	50 (67.6)
• Spouse	14 (18.9)	• Alzheimer's dementia	24 (32.4)
• Adult child	9 (12.2)	• Frontotemporal dementia	
• Other*			

\*Friends and other relatives.

**Table 2.** Characteristics of the carers and the persons with young-onset dementia (YOD) in the qualitative part of the study.

Carer		Person with YOD	
Age, yrs (SD)	56 (12)	Age, yrs (SD)	64 (3)
• Range, yrs	36–73 (61.5)	• Range, yrs	60–70 (61.5)
• Sex, n (%)	5 (38.5)	• Sex, n (%)	5 (38.5)
• Female		• Female	
• Male		• Male	
Relationship, n (%)	10 (76.9)	Diagnosis, n (%)	12 (92.3)
• Spouse	3 (23.1)	• Alzheimer's dementia	1 (7.7)
• Adult child		• Frontotemporal dementia	

35). Nine of the interviews were conducted in the informants' homes, one at the interviewer's workplace, one in a meeting-room at a hotel, one at a hospital, and one at a university office. The last author (AJ) performed the interviews, and the recruitment of informants continued until the last author found repetitive descriptions from the informants as well as nuances in the prefixed topics (Malterud et al., 2016). The interviews which lasted from 26 to 70 (mean = 53) minutes, and in total 689 min. A professional typist transcribed the tape-recorded interviews verbatim within two weeks. The interviewer conducted a quality control by listening to the tapes while reading the transcripts.

The interviews were based on a theoretically driven interview guide with six open-ended thematic questions that focused on the informants' experiences related to the everyday life and needs of the persons with YOD. The thematic questions were about daily activities, social network and close relationships, behavioral changes, safety, and economy, in accordance with the six thematic questions asked in the quantitative part of the study (Reynolds et al., 2000). The interviews were performed as dialogues focusing on the six main questions asked. Depending on the replies, the aspects and ideas the informants raised led to further questions to obtain more information. The questions are listed in Table 3. The dialog and the length of the interview will vary by the experiences the caregivers have, their descriptions of their experiences and their reply to the follow-up questions given (Berg & Lune, 2012, p. 127–128).

## Analysis

### Analysis of the quantitative data

The analyses were performed using Statistical Package for the Social Sciences (SPSS) (Mann Whitney, 2007) version 24. Categorical variables were described by their frequencies and percentages, and continuous variables by their mean values and standard deviations (SD). Comparisons between the two diagnostic groups were analyzed with the non-parametric Mann Whitney U test for ordinal data. One of the first authors (LH) was responsible for the analyses.

### Analysis of the qualitative data

The transcribed data were analyzed using a theoretically deductive approach focusing on the predefined six topics in the interview guide. The method for manifest thematic analysis was used to identify, analyze, and view both coincident and divergent patterns or codes in the total qualitative data material (Braun & Clarke, 2006, p. 87–93). The analysis process began with listening to audio files several times to become familiar with the data material. The data material was then read, and the initial thoughts about what was important regarding the six topics took shape. Interesting aspects from each interview were identified and labeled with descriptive codes. Codes with similar meanings were organized in the same category. Some of the

codes were used in more than one category. Reviews of transcriptions and codes were carried out to see if each code reflected the meaning of the text in the transcriptions. The codes were then organized in overall themes covering the pre-existing topics of interest, and topics not relevant to the aim were not included in the further analyses.

The interview material was thereafter read a second time, and a critical review of the topics was carried out to ensure that the data material and the results were consistent. The process of defining and giving precise and descriptive names to the themes was extensive and analytical. After several rounds, it resulted in the names presented in the results section. Moreover, quotations that illustrate the theme in a nuanced way were selected and added to the result presentation. The author AJ was primarily responsible for the analysis, but the process was continuously discussed with the author A-SH.

## Ethics

The study followed the ethics outlined in the revised Declaration of Helsinki (World Medical Association, 2013) and both sub-studies were approved by the Regional Committee for Ethics in Medical Research, Southern Norway (number 2013/2149 and number 2013/2141), and the Norwegian Data Protection Authority (number 36797 and number 36410). Furthermore, all the informants received verbal and written information about the study before partaking in it and gave also written consent. The persons with YOD provided informed consent to allow their family carers to contribute informant data about the needs in everyday life that persons with YOD experience.

## Results

The quantitative results will be presented first, followed by the qualitative results regarding everyday life that the persons with YOD face, including daily activities, social network, relationship, behavior, safety, and economic situation and needs.

### Quantitative results

The quantitative results are presented in Table 4.

Around 25% of the 74 family carers reported unmet needs in daily activities, social network, and the ability of the person with YOD to manage their finances (Table 4). Relatively few family carers reported unmet needs concerning behavioral changes and safety issues. Only one family carer reported that the person with YOD had unmet needs concerning their close relationship. When comparing the reported topics of needs in the two diagnostic groups, the family carers of persons with young-onset FTD reported significantly unmet needs due to behavior ( $U=781, z=-2.182, p=.003; r=.23$ ) and close relationship issues ( $U=1216, z=-2.829, p=.005; r=0.3$ ) compared to carers of persons with young-onset AD.

### Qualitative results

#### Daily activities turned upside down

The family carers observed that the daily activities of the persons with YOD were massively affected and restricted over time, which then impacted the carers' daily activities as well. The family had to organize and take over most of the practical work at

**Table 3.** Overview of the questions asked to the carers of a person with young-onset dementia (YOD).

1. How do you experience daily life and the daily activities of the person with YOD?
2. How do you experience the social contacts of the persons with YOD?
3. How do you experience the close relationships of the person with YOD?
4. How do you experience the behavioral changes of the person with YOD?
5. How do you experience safety of the person with YOD?
6. How do you experience the economic situation of the person with YOD?

**Table 4.** Needs reported quantitatively by the carers,  $n = 74$ .

Differences between the diagnostic groups measured by the Mann Whitney U test. Significance level set to .05.					
Items*	No need n (%)	Met need n (%)	Unmet need n (%)	Unknown/ missing n (%)	AD vs. FTD (p-value)
Daily activities					
Does the person have problems with regular, appropriate daily activities?	37 (50.0)	19 (25.7)	18 (24.3)	–	.718
Social network					
Does the person need help with social contact?	41 (55.4)	13 (17.6)	19 (25.7)	1 (1.4)	.785
Close relationships					
Does the person have close relationship with someone, a spouse, a relative, or friend?	66 (89.2)	5 (6.8)	1 (1.4)	2 (2.7)	<b>.029</b>
Behavior					
Is the person's behavior dangerous, threatening, interfering, or annoying to others?	56 (75.7)	11 (14.9)	7 (9.5)	–	<b>.005</b>
Safety					
Is the person a danger to themselves?	67 (90.5)	3 (4.1)	4 (5.4)	–	1.000
Is the person at inadvertent risk to themselves?	55 (74.3)	9 (12.2)	10 (13.5)	–	.138
Is the person at risk from others?	65 (87.8)	2 (2.7)	7 (9.5)	–	.221
Economy					
Does the person have problems managing or budgeting their money?	27 (36.5)	29 (39.2)	18 (24.3)	–	.674

\*Items from the Camberwell Assessment of Needs in the Elderly.

home. One husband expressed: *It has been a process taking over the responsibility of everything, that is a lot to keep up with, losing the anchorage at the same time as having to make several decisions.* Participant B-002

Further into the development of the disease came a point where the person with YOD could not be left at home unattended. The spouses and adult children felt that they constantly had to look after their spouse/parent. The person with YOD needed them day and night. Then, the family member to persons with YOD started asking for care, even if it was painful for them to ask for assistance. They expressed that this process went quite well. They were able to acquire a place at a day care centre for the person with YOD some days a week. This helped to some extent, as it allowed them to be able to rest. One husband expressed: *Yes, it is a breathing hole. So, all other hours at home I am on duty from the morning when we wake up and until bedtime.* Participant O-022

The family carers described that the situation regarding the person with YOD made it difficult to live the life they knew from before. The person with YOD had limited abilities and was affected in all aspects of daily living; this forced the families to put their own lives on hold. It became impossible to perform their usual daily life activities. When daily activity challenges increased, the family carers' opportunities to stay at work diminished. One wife expressed: *I get sad when I think about that it is not possible to work anymore. The last year I had to go straight back home after work. Sometimes, I also had to leave work earlier because of him. I miss being able to participate in things that I am interested in, and I miss being with colleagues.* Participant T-004

At this point, the process of determining whether it was beneficial to apply for nursing home placement began. This process was described as a great struggle for the informants. When nursing home placement was established, their role continued with visits, walking tours, and home visits. Some persons with YOD needed practical help at the nursing home from their spouses too, which spurred a feeling of insecurity from one wife, who expressed: *I must buy new clothes all the time. I also use a lot of energy in explaining to health personnel how he is used to dress, and not with sweatpants. I am a bit insecure whether his days there are ok.* Participant V-014

### **Involuntary loss of previous social network**

The informants expressed that being open about the dementia disease and having an open attitude made it easier to socialize

and get support and help from friends, both for the persons with YOD and themselves. Even so, the informants were sometimes afraid of asking for support from friends. One daughter expressed: *It is good to be open at the children's school and at work, because then it is easier for others to understand when they see her in shops or walking about in the neighborhood.* Participant V-016 However, they also expressed that the persons with YOD lost friends, and their social network began to shrink.

Further, health personnel were informative and encouraged the family carers to spend some time to themselves to keep up with their own activities and social circles, but it was draining to attend social activities and gatherings when continuous support of the person with YOD at home took up all their time and energy, without necessary covering their needs.

### **Losing close relationship, but maintaining a friendship with the spouse**

The informants expressed that they and the person with YOD had lost much of their close relationship. They did not talk about feelings, needs, or problems. The intimate life between spouses was gone, but the friendship remained. One wife expressed: *When you change diapers and clean up after your husband, the desire for the intimate moments with the spouse disappears.* Participant T-004

Others described how it had become a different marriage for both. For example, a spouse expressed that when the person with YOD no longer understood how to take a shower, the easiest way to be of help was to take a shower together. They realized that the person with YOD never would return as the spouse or parent they loved- they were lost to them. One husband said: *Our sadness is that we thought that we should be given 10 years before illness overtook us.* Participant O-022 Another expressed that with the disease, it was difficult for her mother to be the grandmother of her children as she is no longer able to take care of and look after them, thus unable to build a close relationship with them.

Further, the informants expressed how the process of applying for a nursing home placement in the best interest of the person with YOD had affected their close relationship. The children and spouse felt guilty in admitting their parents to a nursing home. They felt as if they were giving up on the person with YOD, or they felt impotence, not being able to cover their needs well enough. But even if the close relationship has dissolved, they try to keep what is left of a relation. One wife said: *Sometimes I bring him back home, and we have a snack before returning. That works out!* Participant V-014

### ***Unpredictable behavior adds burdens to a changing life***

The informants described different sorts of behavioral changes in the person with YOD. It could be aggression in the form of trying to hit or throw things at them— a behavior that was not normal. The person with YOD could not explain why they were aggressive when the family carer asked for an explanation. Such behavior also occurred in the nursing home. Aggression frequently occurred in situations related to personal help, such as changing clothes, toilet visits, and other intimate situations. The person with YOD expressed frustration towards the family carer when he or she was unable to explain why they were irritated. One daughter said: Now, when she has been very ill, then it has happened sometimes that she has been very irritated. Such behavior started just before she moved to the nursing home and now when she is there. I think that she is very confused! Sometimes, she in a way tries to fight with us. It hurts for the grandchildren to see that, and for the rest of the family also of course. Participant B-003

Further, they observed that the person with YOD was afraid of being alone. They might start to walk around in the house day and night looking for someone, or simply stay close to a family member all the time, even during the night. Sometimes, the family carers noticed the person with YOD walking around making strange sounds and seemed anxious. All this resulted in sleep disturbance for both the person with YOD and the family carer. The persons with YOD became more and more dependent upon others, and they could not meet their needs. One daughter said: My mother came here every day when the children had come home from school, and she stayed here until the evening. She could take off her clothes when sitting in the wardroom, just in front of my son. That was not ok! When she started to visit us during the night there had to be a change. Participant V-016

The family carers further expressed that they experienced passivity from the persons with YOD, who lacked insight on many situations. In addition, they noted that the environment affected the person with YOD's behavioral changes, even in a nursing home setting. The person with YOD also avoided other family members. As the disease made their behavior more unpredictable, the family carers were afraid of bringing the person home after admitting them to a nursing home or go for a walk with them when visiting them at the nursing home, because they were insecure of what might happen. One of the daughters said: I am afraid that I will have to argue with her bringing her back to the nursing home. So, then you do not dare to bring her outside or home. Participant B-003

***Health and life risks.*** The family carers relayed that the person with YOD experienced safety risks when he or she was on their own. For example, in the early phases of the disease when driving a car or later on when going out alone. One of the daughters expressed changes in driving patterns in the early phases of the disease: We were just unsure about her driving competence and unsure whether she would take the car and drive when she had been drinking wine. Does she understand that she cannot drive when she has been drinking alcohol? That was something we were insecure about? So, we took the car home to our house. Participant V-016

Further, they expressed that the person with YOD could get lost when they were out walking on their own, thus posing a

threat to themselves. A phone with Navigation System using Timing and Ranging—Global Positioning System (GPS) gives carers the ability to call the person with YOD and locate them, thus increasing their safety in everyday life. They also expressed that they organized transport when the persons with YOD went to visit friends so that they would not get lost using public transport. The person with YOD and the family carers felt fear when the former went to work because they could go out and get lost. One daughter said: I have been afraid because she has stopped eating and started to walk about in the area here, day and night. Friends have found her. I am afraid that someone could harm or abuse her. Participant V-016

The family carers expressed that they were aware that dangerous things could happen, and it was important to keep the home safe for everyone. But they also noted that the persons with YOD were not active at home, for the most part not doing what they used to do before they got dementia. At home there were few risks of danger, but they expressed a fear of what could happen during the night. An alarm at the front door has proven to be useful for one wife, who said: Being safe and feeling safe is hard and a consequence is that I sleep very badly. I am constantly on alert. Participant B 002

### ***Economic insecurity for future life and caring costs***

The informants expressed that the disease did not presently cause the person with YOD and their family economic difficulties. Still, during the development of the dementia, the spouses expressed that the economic situation had changed because of a lack of maintenance on the house for years because of the person with YOD's decreased practical function. As a result, the spouses had to hire services to keep the house in shape. Moreover, the situation terminated their work career early. One insecurity was linked to the expenses of the health services. One wife said: I am insecure about the pension, the costs for the nursing home service, and the lack of information about the short-stay costs at the nursing home. Participant V-014

Further, the informant described that they had arranged advance directives for the future of the family situation, both for the person with YOD and for themselves. This was a document that the family agreed upon. They also had to change routines in handling payments and bills, routines that the person with YOD used to be responsible for but could no longer handle. This task was new for some spouses and was considered an additional burden for some.

## **Discussion**

Six theoretically driven topics (daily activities, social network, close relationships, behavioral changes, safety, and economy) from the quantitative and qualitative sub-study results will be discussed.

All family carers expressed in the individual interviews demanding and large changes in the person with YOD's daily activities. The family carers described the difficult process of asking for more formal services due to the increasing challenges and needs that arose in the person with YOD's daily activities. Several qualitative studies have underlined that the person with YOD, but also their carers, have challenges with daily activities and would benefit from more support than they received (Bakker et al., 2014; Cations et al., 2017; Millenaar et al., 2016). The carers gender might influence what the carers

receive help with or have challenges with, (Thorsen & Johannessen, 2023) and likely, also to what extent the voice of the person with dementia is heard (Johannessen et al., 2018; Trindade et al., 2020; 2023). Even so, when using CANE, half of the carers reported that the person with YOD had no needs for support to conduct regular daily activities. What are the reasons for the discrepancy? The time between diagnostic work-up and the time for the inclusion in the study varies greatly for participants in both the quantitative and qualitative sub-studies, but mean time from diagnoses to inclusion is somewhat longer in the qualitative study, and differences in experiences may be due to a broader spectrum of experiences because a possibly rapid changes due to aging or the disease. We may speculate that part of the differences exists because it is harder for a carer to define the changes and needs in their daily activities using a systematic interview with fixed responses compared to talking about the person with YOD's changes, challenges and needs in a more open interview without pre-defined questions and response options.

The qualitative study showed that the person with YOD had lost much of their social network and close relationships, whilst the friendship between spouses remained. Expected boundaries and limits due to the disease made it difficult for the person with YOD to keep up with their social activities and relationships, something that is also pointed out in a meta-synthesis (Eriksen et al., 2016). Family carers of persons with young-onset FTD reported significantly more unmet needs related to close relations compared to carers of persons with young-onset AD. This is expected from the inherent personality/behavioral changes and following demands caused by frontal dysfunction. In the interviews, the family carers did not focus much on unmet care needs due to behavioral changes, but rather on how the disease had changed their social relations and the remnants of their close relationships. However, only one of the interviewed participants was a family carer to a person with FTD. Other studies point out that disruption of close relationships must be dealt with and accepted by the carers and family members (Chirico et al., 2022; Egilstrod et al., 2019; Johannessen et al., 2017). So, when only one of 74 (1.4%) family carers reported unmet needs with close relationships and one in four reported unmet needs with social relationships for persons with YOD, these results may more likely indicate an acceptance that nothing could be done or changed, and one just had to make the best of what is left of the relationships. This suggests an ability and willingness to adjust to demanding stressors. On the other hand, another study has shown that people with dementia may feel less embarrassed in the presence of family and friends because of low self-awareness due to limited mental capacity (Trindade et al., 2023) and thus do not experience challenges regarding close and social relationships.

The qualitative results showed that the carers experienced unpredictable behavior as an additional burden to a changing life. This could be aggression, or just irritability, a behavior non-characteristic of the premorbid personality of the person with YOD. Furthermore, the person with YOD could be perceived as afraid, restlessly ambulating or staying close to a family member 24/7. Anxiety and other behavioral symptoms can be a sign of the disease, but can also be the result of the care provided by the carer or by society (Bakker et al., 2014). In cases with aggression and anxiety, both the person with YOD and the family carer often ended up with sleep problems. However, the quantitative results found that family carers to persons with FTD

reported more behavioral unmet needs than family carers for a person with AD. Overall, three in four family carers reported no needs related to changes in behavior, and only one in ten reported unmet needs related to various sorts of behavior. This underscores a great discrepancy between the results in quantitative and qualitative data. Some of the discrepancy may be due to the differences in sampling but also in time perspective, as the quantitative results reported a snapshot of the situation, at the time they were asked the questions, whereas the qualitative interviews provided a clearer view of development over time. The discrepancy may also result from the questions in the inventory being too superficial, or that the carers found it difficult to answer questions about behaviors worded as 'dangerous, threatening, or annoying to others'. They are being protective and do not want to speak derogatorily about the person with dementia. Thus, the results may underline the importance of asking carers about their situations and their eventual needs for support in their unpredictably changing life more carefully (Robinson et al., 2011).

According to the interviews, the family carers observed safety risks for the person with YOD when they were on their own. An accident could happen, and they could injure themselves, but also hurt others. To increase safety in everyday life, the family carers used GPS-tracking to locate the person with YOD, but also set an alarm at the front door, which was activated when the person left the house. The carers also stopped working, and they limited their social activities to avoid safety risks. The quantitative results showed that about 15% of persons with YOD had unmet care needs concerning the risk of harming themselves involuntarily, and about 10% of them had unmet care needs concerning the risk of harming others, regardless of whether they lived at home or in a nursing home (Johannessen et al., 2017; Tookey et al., 2021; Wammes et al., 2021). But three out of four family carers reported no safety risks - possibly due to the precautions already in place.

One economic consequence of the disease was that the family carers had to hire services to maintain their homes. The qualitative sub-study also showed that the family carers had taken over the family finances since the persons with YOD were no longer able to handle economic issues. As handling of economy requires a complex set of cognitive abilities (e.g. numeracy, memory, abstract thinking, sense of time etc.), this task is impaired in an early phase of dementia, regardless of the type of dementia (Chow et al., 2016; Johannessen et al., 2017; Kimura et al., 2015; van Vliet et al., 2010). The quantitative results showed that about one fourth of the persons with YOD had unmet needs in handling and budgeting their economy. The unmet needs reported quantitatively is high as family carers described they had mostly taken over the tasks completely.

To sum-up, we found that the quantitative and qualitative study gave somewhat diverging results. With the exception of economy, use of the CANE interview resulted in less unmet needs reported by the family carers compared to the information that was revealed in the qualitative interviews. A similar result was shown in a study of carers of persons with young-onset FTD (Tookey et al., 2021). The authors in that study suggested that this may reflect a reluctance to report challenges and unmet needs when assessed by quantitative methods as compared to qualitative interviews. We agree and suggest that this may be due to the format of systematic interview covering the delicate and complex range of disease-related problems and unmet needs. This phenomenon supports the decision to

use mixed methods when assessing challenges and needs in everyday life. However, we cannot overlook the possibility that divergence of some of the results are reasoned in CANE, which aim to more objectively measure unmet needs, while with qualitative interviews it is more difficult to separate between needs covered and not covered by family carers.

## Strengths and limitations

The strength of the present mixed-method study is that using this approach, a broader understanding of the carers' experiences can be achieved and may explain why interviews and the use of scales sometimes differ.

A limitation of the study is that persons with YOD themselves were not included in the mixed-method study as a source of information. Several studies have shown that they are able to express their needs, and it is important to listen to their perspectives (Beattie et al., 2004; Johannessen et al., 2018; Thorsen et al., 2020; Trindade et al. 2023). Another limitation is the small sample size, and the time gap between the diagnostic work-up and study participation, both in the quantitative and qualitative sub-studies, and the inclusion of only one family carer of a person with young-onset FTD in the qualitative part, which may affect the descriptions of experiences from other family carers of persons with young-onset FTD. These limitations could limit the transferability of the study results to the YOD dementia population.

Another limitation is the cross-sectional data used. When using a questionnaire, the picture of the situation is presented at just one point in time, in contrast to interviews, which provides a picture of the needs and situation over a period. Due to the mixed explanatory concurrent design, the thematic themes in the qualitative results became quite closely linked to the six predetermined topics of interest. This made it simpler to integrate the quantitative and qualitative results in the discussion. However, according to thematic analyses by Braun & Clarke (2006), p. 93), the development of the themes were likely somewhat restricted.

## Conclusion

In the quantitative questionnaire, one in four family carers reported unmet needs regarding their spouses' or parents' social networks. The qualitative dataset showed that everyday life had changed for both the person with YOD and the family carers, and their situations were massively affected and restricted. Whilst the person with YOD had lost many of their social companions and close relationships, the friendship between the spouses remained. Unpredictable behavior likely added problems, needs and burdens to a changing life. The disease did not have much influence on the economic situation of the family since the carers handled the finances for both the person with YOD and themselves.

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