

What are the educational and support needs of family carers looking after someone in the early stages of Alzheimer's disease? A qualitative retrospective approach

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Abstract

The current study aimed to identify the educational and support needs of family carers of people with dementia in the early stages of dementia by employing a qualitative approach with retrospective semi-structured interviews with family carers of people in the later stages of Alzheimer's disease (AD). Semi-structured individual interviews were conducted via telephone or Microsoft Teams video call. Purposive sampling was used to recruit twelve family carers of people with moderate or severe (AD). An interview guide was used to explore the retrospective views of the carer's educational and support needs in the early stages of AD. The interviews were audio-recorded transcribed and analysed using thematic analysis. Three overarching themes were identified. Theme 1 highlighted that family carers experienced frequent an overwhelming need to fulfil a family obligation and feelings of guilt to seek help, which acted as barriers to seeking support, in the early stages. In theme 2, family carers rarely received support in the early stages and available resources were limited to self-help materials. Finally, in Theme 3 family carers wanted to receive interpersonal tailored support to seek practical advice and to learn psychological skills to build resilience in the early stages to overcome emotional challenges. The development of interventions that are specifically designed for family carers in the early stages is critical. The key components to be considered for future interventions are discussed.

Keywords: informal caregivers, dementia, anxiety, guilt, diagnosis

What is known about this topic?

- Exploring dementia carers' specific needs is critical for the planning and delivery of community services and for the provision of appropriate support.
- Carers of people in the early stages of Alzheimer's disease (AD) struggle to recognise their own needs.
- Exploring the retrospective views of later-stage carers can provide valuable insights.

What this paper adds?

- Carers of people with AD experience several challenges in early stages, such as extensive worries, the need to fulfil a family obligation and feelings of guilt.
- Carers wanted to receive interpersonal tailored support from healthcare professionals.
- Interventions to support the acceptance of the diagnosis and to cope with the emotional challenges that carers have in the early stages are needed.

Introduction

Caring for someone with dementia can be physically and emotionally challenging and it can have a negative impact on the social, psychological and physical wellbeing of the carer (Ferrara et al., 2008; Richardson et al., 2013). This results in family carers of people with dementia often having high levels of physical burden and psychological distress (Collins & Kishita, 2020; Kaddour & Kishita, 2019). Therefore, exploring family carers' specific needs is critical as this information can lead to the successful planning and delivery of community services and care plans, to the referral of carers to appropriate support and resources and to design research programmes and interventions to improve carer outcomes (Novais et al., 2017).

Recent comprehensive systematic reviews on the needs of informal carers of people with different types of dementia demonstrated that the most explored topics of carer's needs in the literature were: information on the disease, support for the carers from others, coping with caring and behavioural symptoms, support from community services related to patient care (Bressan, Visintini & Palese, 2020; Queluz et al., 2020; Novais et al., 2017), financial issues and safety (Novais et al., 2017), needs surrounding physical health (Queluz et al., 2020) and finding a balance between care duties and their own life and needs (Bressan, Visintini & Palese, 2020). In these reviews, the most included studies used a quantitative approach although qualitative studies were also eligible. Using a quantitative approach to assess dementia carers' needs may allow exploring a larger number of topics simultaneously in a larger sample. However, qualitative research is also valuable as it can explore aspects of complex behaviours, attitudes, and in-depth specific needs and experiences from the standpoint of the participant, which may vary across family carers (Braun & Clarke, 2013; Pope & Mays, 1995).

Several limitations also exist for qualitative studies in this area. Existing qualitative

studies on carers' needs are often focused on carers of people with moderate to severe dementia (Farran et al., 2004; Shanley et al., 2011) or do not differentiate the results by dementia stage, making it difficult to generalise those findings to carers of people with dementia in specific stages such as the early stages (ES) (Peterson et al., 2016). The needs of family carers of people with dementia in the ES may be qualitatively different from those caring for people with moderate to severe dementia as physical support needs of the care recipient may be limited due to the level of independence at the ES.

There are a few qualitative studies, which aimed to explore the experiences of family carers of people with dementia in the ES (Lee et al., 2019). However, these qualitative studies mainly focused on the experiences of the diagnostic process and the transition to caregiving role rather than directly asking about the educational or support needs during these times. There is only one qualitative study, which used focus groups to directly explore the needs of family carers of people with dementia in the ES (Boots et al., 2015). Nevertheless, this study also included carers of patients with mild cognitive impairment and carers of people with different types of dementia. Furthermore, the sample was not large enough for such a heterogeneous population, making it difficult to draw a robust conclusion.

To overcome the limitations of previous research the current study aimed to identify the needs of family carers of people with dementia in the ES by employing a qualitative approach with retrospective semi-structured interviews with family carers of people in the later stages of Alzheimer's disease (AD). In order to reduce the heterogeneity of sample characteristics, AD was chosen as it is the most common cause of dementia (Alzheimer's Association, 2019). The data was collected from carers of people in the later stages of AD and explored the experiences of caregiving in the ES retrospectively, as previous studies suggested that family carers of people with dementia in the ES are hard to identify as they often do not see themselves as carers (Boots et al., 2015; Carduff et al., 2014)

or they struggle to recognise their own needs due to difficulties in accepting the changed circumstances and fear of stigma (Boots et al., 2015; Peterson et al., 2016). The retrospective views of later-stage carers can provide valuable insights as they allow to explore educational and support needs during the ES, which could have an impact for a prolonged period of time (Boots et al., 2015; Jenkins & Feldman, 2018).

Methods

Study Design

A qualitative retrospective approach was employed to explore the experiences of caregiving in the early stages of Alzheimer's Disease (ESAD) from the perspective of unpaid family carers. Semi-structured interviews were conducted with family carers of people with moderate to severe AD.

Ethics

The study received approval from the [text removed for blinding].

Setting

Due to the COVID-19 pandemic, the interviews were conducted via telephone or Microsoft Teams video call, depending on the carer's preference.

Participants and recruitment

Purposive sampling was used to ensure that the maximum variation of viewpoints was obtained. It is estimated that 60 to 70 per cent of the family carers are female in the UK (Glasby & Thomas, 2019). Therefore, the study aimed to maintain this proportion in the final sample. Previous studies also suggest that the experiences from spouses and children looking

after someone with dementia can differ due to the relationship (Brodaty & Donkin, 2009; Glasby & Thomas, 2019; Jenkins & Feldman, 2018). Thus, it was aimed to recruit female and male participants with different types of relationships with the care recipients to ensure that the sample was representative of the targeted population.

The participants included in the study had conversational English and the capacity to consent for themselves; were at least 18 years old; were an unpaid carer with a first-degree relationship (spouse/partner or adult child) with a person with AD, and were caring for a family member with moderate to severe AD, according to the Frontotemporal Rating Scale (FRS) (Mioshi et al., 2010). The study aimed to recruit participants until the sample held sufficient information power, as determined by items such as study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy (Malterud et al., 2016). Participants were purposively sampled from other ethically approved large dementia studies led by the authors. These participants had already given consent to be contacted for future research.

Data collection

After obtaining informed consent via post or electronically, potential participants were asked to attend an initial screening assessment via telephone or Microsoft Teams video call. The screening assessment aimed to assess the participant's eligibility by checking the dementia severity of the care recipient using the FRS (Mioshi et al., 2010). The FRS is a 30-item interview-based measure of patients' dementia severity. This well-established dementia staging tool used largely in research studies (Turró-Garriga et al., 2017) has been validated in various types of dementia patients, including AD (Lima-Silva et al., 2013).

Eligible participants were invited to the semi-structured individual interview, which was also conducted via telephone or Microsoft Teams video call. A doctoral student

(psychologist) experienced in working with family carers of people with dementia conducted all interviews [blinded] that were audio-recorded with the participant's permission. Six participants had taken part in the previous carer study conducted by the first author, which might have helped building the rapport. At the beginning of the interview session, participants were asked to answer some demographics questions, including information about their age, gender, type of relationship with the care recipient, level of education, and work status at the time of diagnosis.

The interviews were conversational, using a blended approach of passive interviewing (allowing the participant space and time to share their narrative) and more active approaches, using questions listed in an interview guide that was developed from the literature and investigators consensus (see Supplementary Material). Participants were reminded that the interview was focused on their experiences during the ESAD throughout the interview to ensure that shared experiences were relevant to the research question. The participants were asked to reflect on (i) challenges experienced in the ESAD; (ii) the type of information and support received for themselves or the person in the ESAD; (iii) their own educational and support needs in the ESAD; and (iv) preferred sources and settings for learning and receiving such support. Due to the highly sensitive and emotive nature of the discussion, there was a protocol in place in case the participants were showing signs of severe stress or depression.

Data processing and analysis

The audio-recorded interviews were transcribed, any identifiable information regarding participants was removed and the data was analysed following Braun and Clarke's six-stage thematic analysis approach (Braun & Clarke, 2006). To ensure the validity and reliability of data analysis, the first coder [blinded] and the second coder [blinded] separately reviewed the initial five transcripts to familiarise themselves with the data and start generating initial

codes. They then met to compare these initial codes to achieve consensus. [Blinded] is a researcher (psychologist) with extensive experience working with family carers of people with dementia with mental health problems and did not have any prior relationship with the participants.

Following this, all transcripts were imported into NVivo 12 and [blinded] used the initial set of codes as an aid to code all the transcripts consistently and generate additional codes as required. Once all the transcripts were coded, [blinded] and [blinded] independently identified potential themes that were then compared to illustrate broad themes and define further sub-themes. Discussions and consensus between [blinded] and [blinded] finalised the mapping and interpretation of key themes and sub-themes.

Findings

Twenty participants were invited to the study and after eight declined to participate, twelve participants were interviewed between September 2020 and January 2021. The interviews lasted between 18-60 minutes. The sociodemographic details of participants are shown in Table 1. Three overarching themes of the educational and support needs of family carers of people in the ESAD were identified: (1) *challenges in the ESAD*, (2) *limited support received after the diagnosis*, and (3) *what carers really want*. An overview of the overarching themes and their categories is provided in Table 2.

Challenges in the ESAD

Feeling guilty for seeking support and information

Carers' insights demonstrated complex emotional difficulties arising from the interpersonal dynamics between carer and their care recipient following the dementia diagnosis. Care

recipients were often unable to accept the diagnosis, making it difficult for carers to directly ask for help in the ESAD. This had a significant emotional impact on the carers, experiencing feelings of guilt due to carers having to do certain things behind the care recipient's back, such as talking about the diagnosis with close friends to seek support or looking for more information about AD without making the care recipient aware:

I mean, the other interesting thing, and I suspect this is fairly common, [care recipient] didn't want me to tell people... and that's quite hard and in fact, I did tell... well certainly our close friends and I didn't tell him that I told some because he didn't want, obviously he knew we told the family and, you know, gradually, I told him that I've told people because, you know, I need some support as well as him. But, you know, I think handling that whole business, you know, obviously, if you got Alzheimer's, your first worry is that everybody is gonna think that you're... you know, that you're some kind of sub-standard person and maybe avoid you or whatever, I don't know, but I mean... people don't do that. But... clearly [care recipient] was embarrassed by the fact of having it and didn't want to tell people. (Participant 011; wife).

The other thing was, even at that stage I felt guilty about reading it in front of [care recipient] you know cos um, it was a very gradual letting go of, um feeling resentful about the um diagnosis of Alzheimer's for her. (Participant 02; husband).

Family obligations – Barriers to seeking support

Participants were often unable to see themselves as carers in the ESAD, which became another barrier to seeking support. Carers felt that looking after the person with AD was their family obligation. This difficulty to see themselves as carers beyond the familial bond impacted the way they perceived their own needs, which some of them only recognised once they had accepted that they were carers:

I've went through a lot on my own before I sought any help with the care and I would pass the carer centre, often and I never thought it is a place that was for me, I didn't think that that was my place. So obviously, the people, you know, who are looking after their family just think, well, I'm doing as a daughter, as a sister, or... I don't know, as a relative, you're doing this job, because you're related to that person, and that's your duty, but you don't realise that you are a carer. (Participant 09; daughter).

She [care recipient's sister] described me as mum's primary caregiver and up to that point, that hadn't actually occurred to me and somehow, that kind of made me think, that made me be more aware of my needs, not just mum's. (Participant 07; daughter).

Significant worries about the future and own health

There was overwhelming evidence in the interviews suggesting that carers experienced numerous worries in the ESAD. Carers often worried about the future, such as how quickly the disease would progress, how the caregiving tasks would impact their own physical and mental health, how they would cope in the more severe stages and the financial impact it may have (e.g. costs of care homes).

Because the only thing, as I say, the thing once you have the diagnosis, is your worry the more you find out about how, not what's happening at the moment but how am I going to cope in a years time or two years time or whatever, when that person's situation deteriorates and you are suddenly finding yourself under a lot more pressure, so I was, was obviously worried about what I'd read about in terms of the potential for how he might deteriorate. (Participant 01; son).

You do worry about what's gonna happen in the future, you sort of worry about the future a bit and, you know, I started to think about, you know, to think about finances, (...) I looked at the cost of care homes if it came to that, cost of, you know, having carers coming to the house, that sort of thing. (Participant 011; wife).

Limited support received after the diagnosis

Feelings of helplessness

After receiving the diagnosis, there was a recurrent feeling of helplessness among most of the carers. The carers felt that they received no or not enough information about AD to help prepare for the future, nor sufficient support to look after their own physical and mental health from healthcare professionals.

No, they, they gave me no other information. When the mental health nurse, got [care recipient] medication settled, she then said 'oh, now I'll hand

you over to the doctor's surgery' and I thought 'oh, someone I'd been able to talk to and get information from', suddenly wasn't going to be doing anything for me, she was just going to hand me back to the doctor's surgery [pause] and I thought 'well, that is really tough'. (...)But really they didn't answer the questions, they sent him off to have a brain scan and they sent him off to other things with no explanation, and I think they need to talk a lot more to the carers, so that we understand what is going on. (Participant 04; wife).

They [healthcare professionals] don't really take into account the carer; they're just dealing with what are they diagnosing this person (...). But they don't, it's not really about carers and how to care for yourself. And I think that would have been really good from the onset, because by the time you get any information about how to look after yourself, you're probably burnt out already. (Participant 09; daughter).

Support limited to self-help resources

Carers expressed that they only received printed or online resources for self-learning about AD in the ES. These materials were often provided by healthcare professionals once the diagnosis was confirmed or carers did their own online research to look for more information from relevant charities. Carers also received limited information about self-care. The only information carers received was often a list of contacts of charities for seeking support or very brief informal advice from their GP or consultant such as being encouraged to ask for help without further details.

I've had a lot of information in books, or I had some pamphlets and all that sort of thing... I can't recall anything apart from that. (Participant 08; husband).

I think one of the leaflets said, obviously if you need support as a carer, here are some contacts that you could read or phone up, but the information was very basic and, and again consisted primarily of just places you could go. (Participant 01; son).

He [GP] said to me '[participant's name] don't wait until you need help, get it now. (Participant 12; husband).

Carers also consistently expressed disadvantages of such self-help resources. The information available on the internet was not practical for carers who do not use computers. Having to be proactive to look for information to seek support and to read a lot of written

information following the diagnosis was somewhat overwhelming for carers in the ESAD.

Non-personalised information, which is very common for self-help resources, did not address their concerns and worries, and carers felt that resources were insufficient when faced with such a difficult situation.

And I think then you have, you know, someone who you care for and you love had that kind of diagnosis it's quite devastating. And I think just handing you a few leaflets, is quite, it's quite cold really, you know, I know, they don't mean to be, but I just don't think that it's appropriate. (Participant 09; daughter).

Let's face it, unless you can be really bothered, you're not going to read, um because the reading, there is so much of it and you sort of think to yourself, 'oh I've got better things to read than this', you know, it's a bit pointless, well it is in my case, um I've got better things to do, then sit down and read a hundred pages of guff from people who probably are very good and know what they are doing but they don't answer the questions that you would like to put to a person, you know what I mean? (Participant 03; wife).

What carers really want

Three key topics emerged from this overarching theme: 1) interpersonal support needed in the ESAD, 2) educational needs in the ESAD, and 3) self-care needs in the ESAD.

1) Interpersonal support needed in the ESAD

There was overwhelming evidence in the interviews suggesting that carers wanted to receive interpersonal support in the ESAD. Carers wanted to have the opportunity to ask questions to healthcare professionals directly after receiving the diagnosis. Carers suggested that this could take a group format (e.g. one-day workshop) with dementia specialists following the diagnosis or a one-to-one format such as regular contact with their GP or a dementia specialist face-to-face or via telephone.

I really feel that with Alzheimer's, when you get somebody who has been diagnosed, it would be really, really helpful to have a day where you are, you and your family, because obviously if you've got several family members, you know, it would be really helpful to have a proper um briefing day for you

and the patient to really help you understand what the issues are. (Participant 01; son).

(...) there should be someone who you could actually talk to who knows about dementia, in all its forms, that you can actually go to them and say, “am I doing the right thing?”, “Who do I go to next to get the information I need?” But there doesn’t seem to be anybody who covers that sort of area of dementia at all. (Participant 04; wife).

Carers also felt interpersonal support outside of the formal healthcare services could be helpful. Talking to other family carers going through a similar experience was something carers wanted to have in the ESAD. Carers suggested that this could include other carers that just found out about the diagnosis, but also more experienced carers, face-to-face but also virtually.

I think you can speak to people about how, you know, if somebody’s going through a similar situation, depending on the type of dementia, how they’ve dealt with that situation, if they found something tough. But you’ve also, you know, you got somebody that has been through it, they can probably help you, give you some support back and some ideas as well. (Participant 06; daughter).

I mean, I guess if there was a group of carers that could get together, but that would be very difficult, because you can’t leave your partner or whatever, so that’s become more difficult, maybe that could be done virtually, you can do these things virtually these days. (Participant 11; wife).

2) Educational needs in the ESAD

Carers wanted to receive more information about dementia in the ESAD. They wanted a better understanding of expected progressions and how to manage the symptoms of dementia and provide better care to the person with AD as the disease progresses from the start. Carers also wanted to receive practical advice such as information on financial and legal aspects and the use of assistive technology.

I think it would be incredibly useful actually, I think that, you know, you do need to give people information, not to scare them too much but I think give them information about what to expect”. (...)I think, information about the sort of things you need to think about and the stage of which you need to

think, I mean thinking about finances and how you're gonna cope with any financial impact in the future is quite important. So, that sort of information would be helpful, if that sort of thing was in a leaflet... it would be helpful what's the cost of care, what's the cost of carers coming to your house. (Participant 011; wife).

(...) it should be a holistic approach, that we are provided information about what is going on with this person, the diagnosis, how to look after, how they need to be looked after, what medications, what exercise, what diet, all the things, lifestyle changes everything that they need. (Participant 09; daughter).

3) Self-care needs in the ESAD

Finally, carers felt that their self-care needs were unmet in the ESAD. As identified earlier, carers struggled to see themselves as carers beyond the familial bond in the ESAD. Thus, carers wanted to receive education and support which can help to increase awareness of their own needs in the ESAD.

Carers also wanted to learn coping skills to build resilience in the ESAD so that they can be more prepared for future challenges. Some carers also expressed the need for receiving more intense mental health support from the ESAD as they considered that caring for someone with AD was stressful, burdensome and isolating.

(...) actually helping them [carers in the ESAD] build resilience at a point when they are not having to deal with those issues but thinking about if things do get worse in a years time or whatever, you know how will you, what are your support mechanisms, who are the people you could turn to in your family or who you live with or your neighbours or whatever, so I think that is another important thing to make that more clear and make people really think carers, as much, well not as much but actually think about a plan of how they are going to cope down the line. (Participant 01; son).

Well, I, I think you know, mental and physical health support would have been important because it, it can be quite stressful so the more you look after yourself the better able you are to withstand the stresses and learn techniques to deal with them (Participant 02; husband).

Discussion

This study aimed to identify the educational and support needs of family carers of people in the ESAD. Three overarching themes were identified in the semi-structured interviews with family carers in later stages. The first theme was the challenges in the ESAD. Family carers manifested feelings of guilt for seeking support, particularly when the care recipient had difficulties in accepting the diagnosis. Perceiving the caregiving tasks as a family obligation was another barrier to seeking support. The frequent and extensive worries about the future and their own physical and mental health were also evident.

The second theme revealed the limited support the carers received following the diagnosis. This occasioned a feeling of helplessness among most of the carers that expressed not having received enough information and support at that time. The minimal support received was often reduced to self-help resources which had several limitations such as non-tailored information not being helpful to address their concerns and worries.

The third theme identified what carers really wanted in the ESAD. This included more interpersonal support following the diagnosis with opportunities to ask questions to professionals but also to talk with other carers going through similar experiences. Carers wanted to receive more practical advice (e.g. legal and financial advice) to look after their care recipient. Provision of support to increase awareness of their own needs and to learn coping skills to build resilience was also identified to be critical in the ESAD.

The third theme (i.e. the need for more interpersonal support and practical support) is consistent with those reported in previous systematic reviews that did not differentiate between the different types of dementias and different stages of dementia (Bressan, Visintini & Palese, 2020; Queluz et al., 2020; Novais et al., 2017), while the first and second themes provided unique perspectives among the carers of people in the ESAD.

Previous studies have found that carers struggle to acknowledge their needs and to accept help in the ES of dementia (Boots et al., 2015). By exploring the retrospective views of experienced carers, this study not only identified the type of information and support that carers needed in the ES, but it also enabled to identify potential factors, that may hinder acceptance of support, such as difficulties in accepting the diagnosis and feelings of the need to fulfil a family obligation. These led to significant emotional challenges such as worries and feelings of guilt in the ES.

Different types of interventions have been developed for dementia carers and have been tested in the research context. There is robust evidence that depression is modifiable across different types of interventions (e.g. psychoeducation, counselling, psychotherapy, occupational therapy, multicomponent interventions) while the sense of competence and self-efficacy in their role may be improved through some specific types of interventions (e.g. psychoeducation, occupational therapy) (Cheng & Zhang, 2020). These previous studies are primarily focused on carers at later stages, and the existing interventions have demonstrated null or weak results for carer anxiety and worries (Cheng & Zhang, 2020). Moreover, the interventions that directly target feelings of guilt in family carers are scarce (Gallego-Alberto et al., 2021), which may be critical for family carers in the ES.

Our findings provided important clinical implications, which highlight the need for multicomponent interventions that are specifically designed for family carers in the ES. These interventions may include dyadic psychological intervention to support the acceptance of the diagnosis, carer intervention aimed at undermining feelings of guilt to seek support and tailored practical advice provided by healthcare professionals and peers to improve anxiety and worries. The co-production and prototyping of such interventions with family carers and stakeholders are key stepping stones towards the successful delivery of support services for family carers in the ES. Despite the advantages of face-to-face delivered interventions, it is

necessary to consider alternative modes of delivery (e.g. internet-/telephone-delivered) that can facilitate access to those carers that cannot leave the care recipient unattended or that have geographical or mobility limitations (Lappalainen et al., 2021).

This study also has some methodological limitations. Although the sample size was large enough to hold sufficient information power and it mirrored the carer demographic characteristics of previous studies, a larger sample would have allowed to identify patterns in each group according to gender and to the types of relationship with the care recipient. It is particularly important to recognise that information on the ethnicity of carers was not collected as part of the study. However, the participants were recruited from the East of England and Greater London areas, where most of the community is White British. It is recommended that future studies explore if the experiences identified in this study are shared by other subgroups of carers such as carers from ethnic minority groups. Moreover, since the researchers who analysed the interviews are both psychologists, the findings could be slightly biased towards psychological factors. Finally, this study used a retrospective approach, and thus findings might have been influenced by recall bias (Althubaiti, 2016).

Conclusion

This study showed that carers of people in the ESAD experience several challenges, such as frequent and extensive worries, overwhelming feelings of the need to fulfil a family obligation and feelings of guilt to seek help. These challenges acted as barriers to seeking support and, since the information and support received after the diagnosis was inexistent or not sufficient, carers ended up having several unmet needs, which may lead to more difficulties in later stages. The development of multicomponent interventions specifically designed for family carers in the ES is recommended. Dyadic psychological intervention to support the acceptance of the diagnosis, carer intervention aimed at undermining feelings of

guilt to seek support and tailored practical advice provided by healthcare professionals and peers to improve anxiety and worries may be critical components of such future interventions.

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Table 1. Demographic characteristics of the sample (N=12).

Family carer characteristics		
Age (in years)	Range	52 - 90
	Mean	69.17
Gender	Female	7
	Male	5
Type of relationship	Wife	4
	Husband	3
	Daughter	3
	Son	2
Educational Level	Secondary school	4
	Vocational diploma	1
	Bachelor's degree	6
	PhD	1
Work status at the time of diagnosis	Part-time	1
	Full-time	5
	Retired	6
Characteristics of people with dementia		
Gender	Female	7
	Male	5
Dementia Severity	Moderate	3
	Severe	9
Number of years since receiving the diagnosis	Range	1.5 - 8
	Mean	2.79

Table 2. Overview of overarching themes and categories

Challenges in the early stages of AD	Limited support received after the diagnosis	What carers really want
Feeling guilty for seeking support and information	Feelings of helplessness	1) Interpersonal support needed in the early stages
Family obligations – Barriers to seeking support	Support limited to self-help resources	2) Educational needs in the early stages
Significant worries about the future and own health		3) Self-care needs in the early stages