



Behavioural disturbances in patients with frontotemporal lobe degeneration focusing on caregiver burden at home and in nursing homes

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Abstract

Aim and objective: To explore the challenges faced by family caregivers of people with frontotemporal dementia and other forms of dementia affecting the frontal and temporal lobes causing behavioural disturbances through a qualitative approach with in-depth interviews.

Background: Studies of different forms of dementia involving degeneration of the frontal and temporal lobes have mainly focused on the neurophysiology and physiology of the disease and on caregivers' health. Few studies have described the challenges and burdens connected with everyday life and in relation to suitable nursing home placement that are faced by family caregivers.

Method and design: This study used a descriptive and explorative design. Eleven semi-structured interviews with family caregivers of patients from special units in four nursing homes were conducted in 2014. Data were analysed based on Kvale and Brinkmann's three contexts of interpretation: self-understanding, common sense and theoretical understanding. Checklist for qualitative studies: Standards for Reporting Qualitative Research (SRQR) <http://www.equator-network.org/reporting-guidelines/srqr/>

Results: Two central themes were derived from the data: changes in behaviour and personality were perceived as incomprehensible, frightening and increasingly difficult to manage. Family caregivers experienced challenges in finding suitable care facilities when they were not able to continue providing home care. Due to behavioural disturbances and lack of relevant competencies among health personnel, family members were often moved between nursing homes.

Conclusion: Pronounced personality and behavioural disturbances such as tactlessness and aggression in a family member with dementia are experienced by caregivers as stressful and burdensome and may lead to feelings of shame and guilt. A lack of suitable care facilities adds to the stress and difficulties of the families and entails an additional and unresolved burden.

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Relevance to Clinical Practice: The study reveals a need for more knowledge among those organising health services as well as healthcare professional dealing with this patient category to ease the burden on next of kin.

KEYWORDS

Behavioural disturbance, dementia, family caregivers, nursing homes

1 | BACKGROUND

The risk of developing dementia increases with age (Brun & Passat, 1996). The behavioural variant of frontotemporal dementia (bv-FTD), a degenerative disorder primarily affecting the frontal region of the brain and causing disturbances in social behaviour and personal conduct, emotional blunting and loss of insight is a common cause of young-onset dementia, but can also occur in older persons (Nunnemann, Kurz, Leucht, & Diehl-Schmid, 2012; Rosness, Haugen, Passant, & Engedal, 2008). However, symptoms involving the frontal lobe are also observed in persons with dementia due to Alzheimer's disease (AD) and vascular dementia (VaD), although these symptoms usually occur in the later stages of the disorders (Brun & Passat, 1996; Rosness, Haugen, Passant, et al., 2008).

The burden of care of patients with frontal lobe degeneration relates primarily to behavioural symptoms such as aggression, change in personality, addiction, irritability, apathy, lack of empathy and depression (Diehl-Schmid et al., 2013; Caceres et al., 2016; Koyama et al., 2018). These dramatic changes in a patient's behaviour may lead to social embarrassment, isolation and stigma (Diehl-Schmid et al., 2013). According to Rosness, Haugen, Passant, et al. (2008), the main symptoms related to a patient's lack of inhibition and personality changes often do not lead to a diagnosis of dementia but are more likely to be diagnosed as atypical depression or other psychiatric disorders.

In a review of 19 papers, Nunnemann et al. (2012) described the situation of caregivers of FTD patients and found that the levels of burden and stress were higher for caregivers of FTD patients than for caregivers of patients with other types of dementia, mainly related to their family member's behavioural disturbances. According to Nunnemann et al. (2012), such disturbances may lead to reduced caregiver well-being and depression, which may in turn lead to the caregiver's neglect of personal needs and social isolation. Küçüközlü, Söylemez, Yener, Barutcu, and Akyol (2017) examined factors affecting caregiver burden by comparing FTD and AD and concluded that patients with FTD were more dependent in terms of functionality and thus required professional care. In general, the functional state of patients with FTD was better than that of patients with AD, but the average functionality score of patients with FTD was found to be lower. This result might be attributed to the characteristics of the sample, which consisted of patients with behavioural disturbances. In a study on nursing care for people with FTD Edberg and Edfors (2008) described difficulties related to behavioural disturbances and patients' lack of judgement and physical

What does this paper contribute to the wider global clinical community?

- Family caregivers of persons living with dementia and behaviour disturbances often perceive everyday life as stressful, accompanied by feelings of shame and guilt.
- Family caregivers' challenges and burdens include problems finding suitable care facilities for their family member with dementia.
- Nursing homes featuring individually adjusted activities for patients living with dementia and behavioural disturbances are needed.

and verbal violations. Problems with memory, orientation and practical abilities occurred to a lesser degree but tended to emerge more strongly as the disease progressed.

The age difference between FTD patients and other patients in nursing homes has also been described as a challenge because patients with FTD are often younger and in better physical condition, and the patients or the relatives may feel that they have different needs than the other patients (Nunnemann et al., 2012; Rosness, Haugen, Passant, et al., 2008). Rosness, Haugen, & Engedal (2008) who studied a group of patients with FTD and their families in Norway found that family caregivers often experienced a life crisis when the family member received the FTD diagnosis and were, in general, dissatisfied with the professional help and information they received.

However, the literature on this type of dementia has mostly focused on the neurophysiology and physiology of the disease and on the caregivers' health. Few studies have described the everyday challenges and burdens that caregivers face in caring for a family member living with FTD or other forms of dementia with pronounced behavioural disturbances. Finding suitable care in a nursing home seems to be another challenge because of the behavioural disturbances of the patients (Rosness, Haugen, & Engedal, 2008) and somehow conflicting needs of shielding in the form of small units as well as the need of physical space. Thus, the aim of the present study has been to explore the challenges of family caregivers of people with frontotemporal dementia and other forms of dementia affecting the frontal and temporal lobes causing behavioural disturbances through a qualitative approach with in-depth interviews.

1.1 | Research questions

1. What types of challenges and burdens related to patients' changes in personality and behaviour are difficult for family caregivers to handle at home?
2. What types of challenges do caregivers experience when a family member with frontotemporal lobe degeneration is admitted to the nursing home?

2 | METHOD

The study used a qualitative, descriptive, explorative design. The retrospective, descriptive part reflected how challenges and burdens influenced family caregivers when providing home care and later after the family member was admitted to a nursing home. The explorative part provided an interpretation and deeper insight into these challenges (Kvale & Brinkmann, 2015).

2.1 | Study population

Four nursing homes in Norway with special units for patients with dementia and behavioural disturbances were selected by the municipal health authorities who also granted permission to conduct this study. The head nurses of the institutions recruited family members of patients fulfilling the inclusion criteria for an interview. Inclusion criteria were family caregivers of patients with bv-FTD and other dementias with degeneration of frontotemporal lobes and behavioural disturbances. Family caregivers of seven patients diagnosed with FTD, five men and two women, aged 62–70 years, were sampled. They stayed at home 6–12 years with behavioural changes and were diagnosed 4–8 years prior to admittance to nursing homes. Five patients had stayed in nursing homes for 2–3 years, whereas 2 patients were in day-care centres when the interviews were performed. Three women had AD (aged 83–93 years). They were diagnosed 6–8 years ago and had been admitted permanently to nursing homes during the two previous years. One man (aged 85 years) was diagnosed with VaD 2 years previously and admitted to nursing home one year later. All patients had degeneration of the frontotemporal lobes and pronounced behavioural disturbances. Diagnoses were based on a comprehensive assessment at a Memory Clinic including cognitive testing and MRI scans of brain conducted prior to hospitalisation in nursing homes. Eleven family caregivers were recruited to participate in individual interviews: nine women and two men aged 46–78 years. The family caregivers were five spouses, four daughters, one sister and one nephew, and all represented close family in the sense of being the primary caregiver before admission to the nursing home. For two of the spouses, the husbands attended an associated day-care centre five days a week, and for the other nine family caregivers, the family members were permanently admitted to a special care unit in a nursing home. All 11 participants were interviewed once. After 11 interviews asking

in-depth questions, we reached saturation in the sense that we experienced extensive repetition of the family caregivers' descriptions of their experiences related to changes in personality and behaviour of their family member they had been caring for at home and the process of finding a suitable care facility.

2.2 | Data collection

The 11 tape-recorded interviews lasted for 45–60 min and were all transcribed verbatim. The interviews were conducted in Norwegian. The family caregivers chose the time and location for the interviews. The interview guide was planned together with healthcare professionals who had experience and knowledge of patients with FTD and behaviour changes. The semi-structured interview guide was based on the research questions and topics derived from other empirical studies (Oyebode, Bardley, & Allen, 2013; Rosness, Haugen, & Engedal, 2008; Ulstein, Bruun Wyller, & Engedal, 2007) containing topics related to the perspective of the families and their experiences providing care at home and the need for a nursing home with appropriate treatment and activities. They also described their family member's reaction after hospitalisation in nursing homes. Prior to the interviews, the interviewees clearly expressed their intention to participate in this study. They said they found it necessary for them to share with society the problems and burdens that are involved in giving home care to their family member with behaviour disturbances. The interview started by asking how the situation was perceived by the family when the family caregiver had the responsibility of providing care at home. The approach was flexible in the sense that the interviews were governed partly by answers and topics introduced by the interviewees. The main goals of the interviews were to understand the family caregivers' perspectives and descriptions of the challenges and burdens when their family member lived at home. They were asked, for example, about support from public health care when needed; such as how health professionals interacted and responded to the needs of the family and the person living with dementia. Caregivers were also asked about the experience they had when trying to find a suitable care facility.

2.3 | Analysis and interpretation

The data were analysed and interpreted according to Kvale and Brinkmann's (2015) three contexts of interpretation: self-understanding, common sense and theoretical understanding using dignity theory. To provide an overall impression of the content, two of the authors read the transcribed interviews several times in their entirety. This process involved searching the entire body of material for patterns and deviances and for similar and contrasting statements. Units of meaning, inspired by the study's aims and by discussions between the authors, were identified in the text. After several discussions seeking to identify the specific units of meaning representing the families' challenges and burdens, the meaning condensation

approach was used. Long sentences were compressed into shorter statements so that the immediate meanings could be rephrased in more concise formulations. The next step, which involved acquiring a critical, common-sense understanding, included a wider frame of interpretation. Further attentive reading and discussions between the authors sought to uncover nuanced meanings related to the initial meaning units. By adding general knowledge about the content of the statement, we made it possible to amplify and enrich the interpretation of the participants' statements. Thus, this part of the analysis generated preliminary themes by labelling the paragraphs and sentences with subthemes. In the last phase, the subthemes were linked together and described through central themes reflecting the research questions (Kvale & Brinkmann, 2015).

Table 1 shows examples of how units of meaning, identified in the text via coding, were condensed and how subthemes and central themes were identified and described. Finally, the data were interpreted and are discussed in the light of theory and relevant empirical studies.

Checklist for qualitative studies: Standards for Reporting Qualitative Research (SRQR), <http://www.equator-network.org/reporting-guidelines/srqr/> Supplementary File 1.

2.4 | Ethics

IRB did the ethical approval of the study. The patients identified for this study were considered too ill to be interviewed. To perform the study in an ethically justifiable way, family caregivers were selected as study participants and received oral and written information about the study from the head nurse in the units where the patients were admitted or stayed in day-care institutionalised. When family caregivers agreed to participate in the study, the nurses acted as the contact between the study participants and researchers. The researchers repeated the information and provided a written copy of the information to the participants concerning the study before the

start of the interview. To ensure confidentiality, all interviews were de-identified with the aim of making it impossible to recognise the study participants.

The study participants received a written letter from the researchers containing the following items: background for the study, what participation involves, what happens to the information, consent to participate in the study and consent to publish information about their family members. All participants signed this declaration of consent (date, place, name, relationship with the patient) and returned the declaration to the researchers.

3 | RESULTS

Important results related to the family caregivers' perceptions of the challenges of having a family member living with dementia at home are ascertained. Incomprehensible changes in personality and behaviour and lack of care facilities contributed to what was described as burdens. These perspectives were retrospective because they were gathered through questions about each family caregiver's challenges during the period when their family member with dementia still lived at home. Other descriptions were provided in a more narrative form at the start of the interview and without the interviewer asking directly about specific challenges.

3.1 | Incomprehensible and frightening challenges and burdens

3.1.1 | Tactlessness and aggression

Participants spoke of the changes in behaviour and personality that they perceived as incomprehensible and frightening. They described a gradual process during which the personality and behavioural changes occurred over a period of years, in which their family

TABLE 1 Examples of themes and structure

Unit of meaning	Condensation	Subtheme	Central theme
"He began to withdraw from his friends; he seemed to be in a bad mood and could be very angry. I felt sad and lonely because of his behaviour." "He could criticise the person next to him and tell him what he thought of him, and I felt embarrassed."	The spouse's personality has changed. The caregiver feels sad, lonely and embarrassed	Aberrant behaviour	Reduced caregiver well-being caused by changes in behaviour and personality
"We tried a day-care centre and short-term hospitalisation, but that did not work out. It was difficult to find a place where she could receive suitable care in addition to activities. She was sent from one nursing home to another. I checked out several nursing homes to find a place and surroundings where she could fit in with her diagnosis and where she could do well."	The caregiver has experienced difficulties finding an institution that can handle the behaviour and offer person-centred activities	The patient was sent to several nursing homes because of difficulties finding care facilities.	Challenges of finding suitable care facilities

member became increasingly difficult to manage. Caregivers mentioned behavioural disturbances such as tactlessness, quarrelsome behaviour and apathy as common early expressions. Increasing aggressiveness, both physical and verbal elicited feelings of fear, leading to a feeling of powerlessness and embarrassment in the caregiver and the family. Other symptoms exhibited by the family members were suspiciousness and signs of paranoia, and there were several examples of family members trying to control their surroundings.

The changes were often gradual and seldom thought of as indications of dementia, possibly because many of the family members were relatively young when the symptoms started. Thus, the diagnosis was often delayed, and it sometimes took a long time before families started to consider dementia as a possible diagnosis. One daughter reported how her mother gradually changed over a period of 10 years without the daughter realising that the symptoms could be related to dementia:

The last summer before she was admitted, she could come to my house up to three times a day ... and I wished that I had understood what had happened to her. Because I did not know what it was ... and, retrospectively, I see [now] that it was a cry for help. Suddenly, she started to walk around in the centre of city, she did not know where she was, and she became very aggressive, yelling at people, calling them bad names. When I had to go and get her at the police station, I realized that I needed help to handle the situation. It was then I truly understood

As stated above, behavioural changes created great difficulties for the caregiver and the family. However, it still took a long time and often a dramatic situation to make caregiver and family members realize that their family member needed help.

3.1.2 | Feelings of embarrassment, shame guilt and loss

Family caregivers said that they felt embarrassed and ashamed to even talk about some of the episodes involving extreme personal and behavioural disturbances. They described feelings of embarrassment and shame and having to apologise when a family member exposed himself or herself to other family members, friends or neighbours. Caregivers told of the family member becoming aggressive during dinners or travels where it was difficult to gain control and where they had to interrupt the dinner or trip and return home. One wife elaborated on how her husband increasingly tended to end up in conflicts with neighbours:

He quarrelled with the neighbours, and I had to protect him against them. The next-door neighbours had some bushes around their carport, and my husband thought they had grown too high. When I returned home, he was standing on a stepladder cutting down the bushes I

had to talk to them to apologize and pay for the damage. It was so hard, and I was ashamed of his behaviour.

Family caregivers also described how their family member gradually withdrew from family and friends in a more subtle way, some becoming moody and increasingly uneasy in other people's company. As some cases demonstrate, this withdrawal was later replaced by increasingly aggressive behaviour. One wife explained how the symptoms gradually changed over the years:

He withdrew, he didn't want contact with old friends, and he was often in a bad mood ... and that was a challenge to me. I felt I did not recognize my husband.[...] Three years ago, he started to abuse alcohol ... he was violent with me, quarrelled with everyone, and it became difficult to live with him. I realized that he needed help. After a while we got help, but I felt I had lost my husband.

Often, family caregivers felt both stress and guilt related to the need to look after their family member and at the same time to be responsible for their own children, spouses and their work. The personality and behavioural changes could also imply different types of risky behaviour because of loss of sound judgement and loss of control, and caregivers often felt that more comprehensive help was needed to ensure the family member's individual needs. By contrast, the afflicted family member often tried to minimise the problems and the need for help. One daughter explained as follows:

It was hard because I had to call her every day, and I had to visit her flat to see what was going on. I also had my own job and my children to take care of. [...] We were worried because she would stop eating and drinking and stop using the toilet. My mother had very little public assistance, but she thought she did very well at home.

3.1.3 | Feelings of being alone

The women, especially the daughters, mentioned that their male relatives contributed less to the continuity of care of the affected family member and were less emotionally involved, and therefore, the women assumed a larger part of the burden. One daughter explained:

I felt the burden of taking care of her on a daily basis, and I felt I was the one who was ... more emotionally affected. I have a brother, and he has a busy job, but he tried to be supportive.

Another daughter also described the feeling of having to be the one in charge and sharing the caring task with a brother who was running a business: "Sometimes I wish that he could contribute more I am the one who always has to get things moving."

Female caregivers in our study claimed that they often ended up with the main responsibility and that they received little help and support from other family members. Thus, receiving the diagnosis, even though it was a shock, enabled them to talk about and acknowledge the disease as well as to start mobilising help through public care.

3.1.4 | Feelings of relief

Caregivers described the relief of receiving the diagnosis despite feelings of embarrassment and shame. Family caregivers of younger people with dementia, who were still working and who had children to care for felt that the period before the diagnosis was particularly burdensome. At the time of the diagnosis, caregivers had reached a point where they realised that something was wrong. They were often constantly alert and under pressure, and at the same time confused and stressed about the cause behind the personality changes. One woman elaborated about how her husband did not receive a diagnosis until he had reached an advanced stage of the disease because of his young age at the time when symptoms appeared:

He was in his late 50s. He was the leader of the (group responsible for) production test equipment in the company After his hospitalization, I found emails from his former manager suggesting that he could retire This was 2 years before he had a computed tomography scan. He had this test because he had difficulty "taking in information." After some time, he called in sick, and I cared for him. Later, my husband was called to a general meeting with our physician, and I was included. The physician wanted to test my husband. He asked (questions such as) what time and date is it now, what's your address and post code, and ... my husband could not answer, he could not remember words and he did not understand his watch I was in shock How was this possible? ... This was such a traumatic situation. Weeks later and after more specific tests, we received the diagnosis.

After receiving the diagnosis, the family caregivers often felt relieved because they were now able to better understand the behaviour of their ill family member. It was also easier to explain the behavioural disturbances to other members of the family and close friends and, subsequently, to avoid some of the shame and stress associated with the many difficult social situations.

3.2 | Challenges met when the decision to move from home was taken

3.2.1 | The difficult conversation

Family caregivers in this study described years of challenges and burdens before they asked for help from doctors or other

professional health professionals. The decision to move their family member, often against his or her will, to a long-term care facility was described as a difficult process for each family. In particular the caregivers told how difficult it had been to tell their family member with dementia that he or she had to move because he or she needed more help than the family caregiver could provide. Often, their family member did not want to move, or did not understand why moving was necessary: thus, the decision was made against their will.

A daughter put it this way:

My mother lived alone in her flat. I lived nearby. Neighbours said they could hear her cry for help and she did not remember how to use the toilette. I really needed help. She was hospitalized against her will, was very angry and said she did well at home.

Often, difficult situations as described above would escalate and lead to an immediate need for professional help and institutionalisation with subsequent complaints and anger from their family member.

3.2.2 | The challenges of finding suitable care facilities

Caregivers described difficulties in finding suitable care facilities for their family member. They emphasised that they lacked information about the types of nursing homes and day-care centres that could meet the needs of patients with pronounced behavioural disturbances and, at the same time, satisfy the patient's need for physical indoor and outdoor activities. The caregivers described in detail how their family member was sent from one unit to another because the staff could not cope with the behaviour. One participant described this process as similar to a "package being sent around by the mail." According to the participants, the staff of the units that patients were sent to often lacked experience and knowledge to manage aggressive behaviour, and the staff also seemed to lack sufficient personnel during working hours. A relative elaborated on the process of finding a suitable place:

My sister lived at home until she was hospitalized for evaluation and treatment. After a few days, the hospital sent her to a nursing home, but she didn't fit in, and she was sent home. She could not live alone and was sent to another nursing home and then to another one. She could not cope with such extensive moving ... and I really had to fight for her, but it didn't help. The responsible health authorities in the municipality ... they are the bosses.

Caregivers described how the people in charge of deciding the type of care and institution for their family member were insensitive and provided little information about the reason why their family member was moved between different care facilities.

One caregiver described an unclear process in which her father had been moved between three nursing homes before they found a small protected unit with competent personnel. However, the patient himself did not feel that he fit in because he viewed the other patients as much sicker than himself, and he repeatedly asked to return home.

One husband told how his wife called him several times a day to say that she wanted to return home. Another told how his family member would run away from the institution, returning home in a taxi, and thus, how these created feelings of ambivalence and guilt. A daughter elaborated as follows:

My mother stayed in her own flat, and she caused a lot of trouble for her neighbours and friends by being rude to them. It was a demanding situation at home ... she was aggressive, and we needed help. After her hospitalization, she was not happy; she ran away, returned home in a taxi, and told me she was sent to hell ... I feel a burden was lifted from my shoulders when I received support, but I felt guilty for a period because my mother was not happy with her stay in the nursing home.

Thus, even though the caregivers felt a sense of relief after obtaining help, it often also created feelings of sorrow and guilt to see their family member lonely or to hear their complaints about being unhappy in the care facility.

3.3 | Experiences with the care facilities

3.3.1 | Experiencing loneliness, isolation and passivity in the family member

According to family caregivers, the family member often expressed unhappiness when they visited them at the care units. The family caregivers tended to describe their family members' room in the institution as an ugly, small and naked room, which often reinforced the guilt related to the family member's obvious desire to return home. Caregivers also observed passivity and isolation after their family member had moved to an institution.

For example, some described the loneliness of their family member being isolated during meals because they would interfere with other patients and, in general, cause disturbances during. One daughter put it this way:

My mother is sitting in this cheerless room with no one to talk to and she is separated from other patients during the meals. The staff do not arrange the meal for her and if we pop in, we see the plate of food lying on the floor. I feel they are helping my mother, and in a way, I feel satisfaction except when it comes to the isolation during meals and her hunger. She is very hungry when we visit her. We are afraid that she is not able to get enough food.

Other caregivers described that they perceived their family member as isolated in their room even though they had a lot of energy and were physically fit enough to walk around in the surroundings of the institution.

One daughter emphasised the lack of possibilities for moving around and going for walks:

My mother is physically very strong and often want to take a good walk around, but she is afraid of walking alone. The staff are busy and there is no one to take her out for a walk.

Family caregivers often described collective arrangements of different activities arranged for the patients, such as tours around in the district and evenings with music and dancing. Often, their family member could not participate in these arrangements because there were too many physically ill patients in the unit to deal with, and their family member needed more or other types of resources to be able to participate. In other words, their family members often tended to demand something different than what the nursing home could offer; such as different kinds of entertainment, activities or skills related to their previous occupation and hobbies in which they were still able to attend.

3.3.2 | Satisfaction with care

There were also examples of caregivers who had good experiences and found satisfactory ways of combining family care and public health care. There were caregivers whose husbands had developed symptoms at an early age and had been through a troublesome period of several years with their husbands at home. After receiving the diagnosis, the caregivers started to look for suitable care options in addition to nursing homes. Because the caregivers were still working, they wanted someone to look after their husbands during the daytime. The husbands were offered a place at a hospital with a day-care centre established for FTD patients. The hospital staff were specifically trained to address deviant behaviour and how to treat patients with this type of diagnosis. One spouse described how the staff managed to handle difficult situations:

He was so angry one day at the day-care centre that he really scared all the patients, but the staff could cope. They managed to calm him down, and they did not accept such conduct.

During the daytime, the family member participated in highly individualised activities and then returned home by taxi in the afternoon. One of the wives elaborated as follows:

He is in a day-care centre now, and I am so happy ... for me, it is necessary for my daily life. I work a full day, and we both have our own rhythm. We wake up and leave the

house together to go to work and the day-care centre. He returns home by taxi in the afternoon. At this centre, the staff offer him activities such as taking a trip to the city, doing some practical things like carpentry ... things he wants to do ... the activities are individually adapted. Family members are provided with support from the day-care centre because this is a difficult situation for the family.

This wife also emphasised the possibility to let her husband stay overnight in the "relief department" in the hospital, which was an offer to relieve the spouse if her husband did not insist on sleeping at home.

Once a month, the family caregivers met with a nurse and psychologist in this day-care centre. These meetings were intended to prevent and manage problems and to identify and support the needs of the family caregivers. This day-care centre seemed to be the only instance in which both the family caregiver and the family member with dementia were relatively satisfied with their daily life in which the type and extent of activities were individually facilitated.

4 | DISCUSSION

4.1 | Incomprehensible and frightening challenges and burdens

The main findings of this study were related to what family caregivers described as behavioural disturbances in the family member living with dementia. Particularly, the time before their family member was diagnosed with dementia and the time before he or she started to receive help through public healthcare services were described as difficult for family caregivers. They considered the marked changes in personality and behavioural disturbances as a "loss" of their loved one, and the families. The caregivers in particular described feelings of sorrow, embarrassment, guilt, fear and loneliness. The family member's behavioural disturbances and difficulties finding suitable care facilities contributed to the challenges and burdens. This main finding is consistent with previous research (Feast et al., 2016; Nunnemann et al., 2012; Ulstein et al., 2007) showing that symptoms and behaviours associated with frontal lobe degeneration cause pronounced changes in patients' personalities and impose burden and stress on caregivers. Nordenfelt (2004) underscores that we should treat family caregivers with respect, tolerance and empathy and he emphasizes that most of us have a basic respect for our own identity. But this self-respect can easily be shattered, for instance by what may be perceived as unfriendly acts of other people. These acts can be related to behavioural disturbances of their family members that humiliated them.

In our study, spouses also felt lonely in the sense of losing their partner and feeling a great sense of responsibility. Furthermore, local authorities had difficulties in finding suitable places where the patients with behaviour disturbances could receive appropriate care. These findings are consistent with a study of caregivers of people with FTD, which found that changes in patients' behaviours and the

interpersonal relationships related to such behaviours were associated with a perception of heavy burden and caregiver stress (Diehl, Mayer, Førstl, & Kurtz, 2003, Caceres et al., 2016).

The most important needs reported by the caregivers in our study were more dialogue and psychosocial support from educated personnel, in particular during the process of finding suitable care options. Regarding Shotton and Seedhouse (1998) and their theory of "Practical dignity in caring", the authors emphasize that we may lack dignity when we find ourselves in inappropriate circumstances, when we feel incompetent, inadequate or unusually vulnerable. The family caregivers feel, in a way, incompetent in taking proper care of the family member when the dementia disease is progressing, and they need suitable care facilities. Family caregivers should be able to feel that they are respected and being listened to when they request help from official health providers.

In our study, we also found that women in particular may be exposed to undue pressure related to the care of a family member with dementia. Studies of dementia in various cultures find, in general, that female caregivers are at risk of having a greater caregiver burden (Besser & Galvin, 2018; Eters, Goodall, & Harrison, 2008).

4.2 | Experiences with the care facilities

The special characteristics of the patients in the current study, particularly their relatively young age, may be why their caregivers experience greater challenges and burdens than other caregiver groups. In a study of the experiences of caregivers of patients with a behavioural variant of FTD, Oyebode et al. (2013) noted that bizarre changes in patients' behaviours impose a heavy burden and lead to isolation. Oyebode et al. (2013) reported that families emphasised the importance of managing the behaviours by "sharing tasks and roles," and thus, family members helping and supporting each other were seen as crucial to coping with the situation. Patients with FTD are often young and in physically good condition, which raises several dilemmas with regard to both coping with the situation at home and deciding on the type of facility needed for the family members with dementia (Peeters, Beek, Meerveldt, Spreeuwenberg, & Francke, 2010). The age differences between FTD patients and other patients in nursing homes make these questions more complex.

Our study shows that caregivers expressed a need for suitable nursing homes or day-care centres that meet the needs of their family member with FTD and other dementias with pronounced behavioural changes. Norway has several nursing homes with small units, but even in these units, the nurses not always manage to cope with patients' behaviour. Our study also shows that the often aggressive and deviant behaviour of patients with FTD requires both protected surroundings and competent personnel. The lack of such resources may explain why these patients, according to our findings, are moved around like "a package," an expression used by the family caregivers who felt that they were not heard by the responsible authorities. They were seen but only as a member of a group of families in need of professional care for their family members. Mann (1998)

developed a provisional taxonomy of dignity and violations. The author refers to the fact that group classification can lead to pride and a sense of dignity but can also lead to the contrary. In our study, family caregivers described that the solutions the health authorities found for their family members were unacceptable, and it felt humbling for them to experience unhappiness in their family member. Mann (1998) underline that by treating caregivers as part of a group, the significance of cooperation with the individual caregiver seems not emphasized, and thus a degradation of dignity of the individual occurs. This seems to be in accordance to Shotton and Seedhouse (1998) and their way of expressing lack of dignity and what makes people feel undignified.

Nunemann et al. (2012) described the difficulties of finding a suitable nursing home or day-care centre to meet the needs of FTD patients and caregivers.

The age differences between the patients with FTD and other patients in nursing home were found to be problematic in that patients with behaviour disturbances were younger and physically in good shape; thus, they did not fit in with wheelchair-using patients.

In a study by Diehl-Schmid et al. (2013), 94 caregivers of FTD patients were interviewed. In 16 cases, nursing homes declined the patient admission or discharged the patient at least once because the staff were overwhelmed by the behavioural disturbances.

A study of patients and care in Norway (Rosness, Haugen, & Engedal, 2008) found that, significantly more patients with FTD than AD patients were admitted to nursing homes for either long or short-term care because of a change in personality associated with behavioural disturbances. The family caregivers in that study tended to be less satisfied with the type and provision of support that they received from the specialist health service than caregivers of AD patients were. Caregivers in the present study told how their family members were excluded from collective arrangements in nursing homes, such as outings and evening activities like singing and dancing because he or she were not able to participate with other patients, as they demanded too many resources. The findings indicate that there are often no plans for individualised activities which is a pronounced need for patients with behaviour disturbances (Diehl-Schmid 2013). In general, family caregivers experienced that their family member was unhappy and dissatisfied, which could result in repeated attempts to escape or a wish to leave the nursing home. Gallagher, Li, Wainwright, Rees Jones, and Lee (2008) who related dignity themes to culture and care, indicate factors that suggest in general the shared values concerning the style and organisation of care that may prevail in an area. This is related to the term "culture" to capture the sense of shared values. Thus, family caregivers wished for, but were often denied, the opportunity to be involved in the care and to express their autonomy and their knowledge.

In the present study, two caregivers (spouses) noted that they had found suitable facilities that were specialised day-care centres where younger FTD patients with behavioural disturbances were activated. Daily activities were described as individualised, and those patients did not seem to resist their daily stay at these centres. Although there were only two caregivers who had this experience,

these findings suggest that the combination of access to individualised activities in different places and competent healthcare personnel may provide a better model of care. A collaborative link between public health care and caregivers at home may prevent the strong feelings of burden and guilt among relatives who must eventually choose to use long-term institutions.

The "medicalisation" of dementia through different control measures does not consider the ways in which the caregiving relationship and the caregiving context can affect a person with dementia and his or her caregivers (Bartlett & O'Connor, 2007). Such considerations may be important, and we suggest that the positive experiences expressed by the families who used day-care facilities and experienced support and information, represent a promising solution and are based on a combination of public and family care. According to Edlund (2002) it is important to be seen, believed and listened to. In this way, the dignity of the families is maintained. However, the success of this combination will depend on numerous factors, such as the patient's behaviour (e.g. severity of aggressive behaviour), the caregivers' resources and wishes, the existence of a specialised day-care centre and the availability of competent personnel. In addition, collaboration and communication are necessary to bridge the gap between care provided by the family and care provided by public services; sharing tasks and roles facilitates appropriate care.

4.3 | Methodological considerations

Our study was based on in-depth interviews with family members of patients with FTD and similar forms of dementia either living in nursing homes or using day-care centres. Our study population may be seen as heterogeneous because spouses, sisters, daughters and nephews of patients were included. All participants were relatives, and we think that the validity of this study is strengthened because the experiences shared were quite similar independent of age, gender and family status (Malterud, 2017).

Methodological rigour in this study was sought by continuous discussion with all co-authors during the research process. All authors met at regular intervals to discuss the study design. Two of the authors independently read all the transcripts from the interviews before the coding frames were agreed upon. The same authors continued to have a detailed and thorough analytical discussion with regard to the development of subthemes and themes that were to constitute the main findings of the study, thereby increasing the overall validity of the study.

5 | CONCLUSION

This paper contributes knowledge related to a highly burdened group of family caregivers and their everyday lives. Family caregivers perceive the care of a family member with frontotemporal degeneration as incomprehensible and entailing frightening challenges in terms of behaviour and burdens. The tactless behaviour and aggression make

the family caregivers feel embarrassed when meeting family, friends and neighbours. The changes in behaviour also cause difficulties in finding suitable care facilities. A lack of care facilities with specialized staff added to difficulties. Families who used day-care facilities and experienced support and information from staff especially trained to cope with behavioural disturbances expressed satisfaction.

6 | RELEVANCE TO CLINICAL PRACTICE

Patients with frontotemporal dementia and other forms of dementia affecting frontal and temporal lobes often have personal and behavioural disturbances creating challenges in connection to nursing home placement. These patients are often young and in physically good condition, which raises several dilemmas with regard to coping with difficult situations and in deciding on the type of facility and care they need. This study shows that the often difficult and aggressive behaviour of the patients required both protected surroundings and competent health professionals trained to facilitate individual activities for the patients. Because of the dementia disease and behaviour deviations, it is often impossible to participate in joint activities. The study shows that moving the patients between nursing homes may indicate a need for more knowledge and experience to handle the patients' behavioural disturbances and communicating with their families. The scheme of allocating adequate nursing home space for patients with this type of dementia does not seem good enough. The offices that manage and assign living units to this group of patients need well-trained staff, but first and foremost, good routines for a close dialogue with the families. This is crucial for how family caregivers experience being met, for the help they receive and lastly for patients and family caregivers experience of a dignified life.

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CONFLICT OF INTEREST

There are no conflicts of interest related to this study.

AUTHORS' CONTRIBUTIONS

Study design: MKR and DN; data analysis: MKR and MS; data collection and drafting of the manuscript: MKR; critical revisions: DN, IU, KK and BL; all authors read and improved the final manuscript.

ETHICAL APPROVAL

The Norwegian Centre for Research Data (NSD, no 34,886) approved the study.

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REFERENCES

- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2), 107–118. <https://doi.org/10.1016/j.jaging.2006.09.002>
- Besser, L. M., & Galvin, J. M. (2018). Perceived burden among caregivers of Patients with frontotemporal degeneration in United States. *International Psychogeriatric Association* 31(8), 1191–1201. <https://doi.org/10.1017/S104161021800159X>
- Brun, A., & Passat, U. (1996). Frontal lobe degeneration of non-Alzheimer type: Structural characteristics diagnose criteria and relation to other frontotemporal dementias. *Acta Neurologica Scandinavica Supplementum*, 94(Supplement 168), 28–30. <https://doi.org/10.1111/j.1600-0404.1996.tb00369.x>
- Caceres, B. A., Frank, M. O., Jun, J., Martelly, M. T., Sadarangani, T., & Cesar de Sales, P. (2016). Family caregivers of patients with frontotemporal dementia: An integrative review. *International Journal of Nursing Studies*, 55, 71–84. <https://doi.org/10.1016/j.ijnurstu.2015.10.016>
- Diehl, J., Mayer, T., Förstl, H., & Kurtz, A. (2003). A support group for caregivers of patients with frontotemporal dementia. *Dementia Sage Journals*, 2(2), 151–161. <https://doi.org/10.1177/1471301203002002002>
- Diehl-Schmid, J., Schmid, E. A., Nunnemann, S., Riedel, L., Kurtz, A., Förstl, H., ... Cramer, B. (2013). Caregivers burden and needs in frontotemporal dementia. *Journal of Geriatric Psychiatry and Neurology*, 26(4), 221–229. <https://doi.org/10.1177/0891988713498467>
- Edberg, A. K., & Edfors, E. (2008). Nursing care for people with frontal-lobe dementia-difficulties and possibilities. *International Psychogeriatric*, 20(2), 361–374. <https://doi.org/10.1017/S1041610207005595>
- Eldlund, M. (2002). *Human dignity a fundamental concept of caring science*. Åbo Akademisk förlag: Åbo Finland.
- Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20(8), 423–428. <https://doi.org/10.1111/j.1745-7599.2008.00342.x>
- Feast, A., Orrell, M., Chalresworth, G., Melunsky, N., Poland, F., & Morris-Cook, E. (2016). Behavioural and psychological symptoms in dementia and challenges for family carers: Systematic review. *The British Journal of Psychiatry*, 208, 429–434. <https://doi.org/10.1192/bjp-bp-114.153684>
- Gallagher, A., Li, S., Wainwright, P., Rees Jones, I., & Lee, D. (2008). Dignity in the care of older people – a review of the theoretical and empirical literature. *BMC Nursing*, 11, 7–11. <https://doi.org/10.1186/1472-6955-7.11>
- Koyama, A., Hashimoto, M., Fukuhara, R., Ichimi, N., Takasaka, A., Matsushita, M., & Ikeda, M. (2018). Caregiver burden in semantic dementia with right-sided predominant cerebral atrophy and in behavioural-variant frontotemporal dementia. *Dementia and Geriatric Cognitive Disorders Extra*, 8, 120–137. <https://doi.org/10.1159/000487851>
- Kükükgüçlü, Ö., Söylemez, B. A., Yener, G., Barutcu, C. D., & Akyol, M. (2017). Examining factors affecting caregivers burden: A comparison of frontotemporal dementia and Alzheimer' disease. *American Journal of Alzheimer's Disease & Other Dementias*, 34, 200–206. <https://doi.org/10.1177/1533317517703479>
- Kvale, S., & Brinkmann, S. (2015). *Interview: Learning in Craft of Qualitative Research Interviewing*, 3rd ed. Oslo: Gyldendal Akademisk.
- Malterud, K. (2017). *Qualitative methods related to medical research*, 4th ed. Oslo: Universitetsforlaget.
- Mann, J. (1998). Dignity in health: The UDHR's revolutionary first article. *Health and Human Rights*, 3(2), 31–38.
- Nordenfelt, L. (2004). The varieties of dignity. *Health Care Analysis*, 12(2), 69–81. <https://doi.org/10.1023/B:HCAN.0000041183.78435.4b>

- Nunnemann, S., Kurz, A., Leucht, S., & Diehl-Schmid, J. (2012). Caregivers of patients with frontotemporal lobar degeneration: A review of burden, problems, needs, and interventions. *International Psychogeriatrics*, 24(9), 1368–1386. <https://doi.org/10.1017/S104161021200035X>
- Oyebode, J. R., Bardley, P., & Allen, J. L. (2013). Relatives' experiences of frontal-variant Frontotemporal dementia. *Qualitative Health Research*, 23(2), 156–166. <https://doi.org/10.1177/1049732312466294>
- Peeters, J. M., Van Beek, A. P. A., Meerveldt, J. H. C. M., Spreuwenberg, P. M. M., & Francke, A. L. (2010). Informal caregivers of persons with dementia, their use of and need for special professional support: A survey of the National Dementia Programme. *BMC Nursing*, 9, 1–9.
- Rosness, T. A., Haugen, P., & Engedal, K. (2008). Support to family carers of patients with frontotemporal dementia. *Aging & Mental Health*, 12(4), 462–466.
- Rosness, T. A., Haugen, P., Passant, U., & Engedal, K. (2008). Frontotemporal dementia – a clinically complex diagnosis. *International Journal of Geriatric Psychiatry*, 23, 837–842. <https://doi.org/10.1002/gps.1992>
- Shotton, L., & Seedhouse, D. (1998). Practical dignity in care. *Nursing Ethics*, 5(3), 246–255.
- Ulstein, I., Bruun Wyller, T., & Engedal, K. (2007). The relative stress scale, a useful instrument to identify various aspects of carer burden in dementia. *International Journal of Geriatric Psychiatry*, 22(1), 61–67. <https://doi.org/10.1002/gps.1654>

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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