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Family caregivers experiences of the pre-diagnostic stage in frontotemporal dementia

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ABSTRACT

Frontotemporal dementia (FTD) is a neurodegenerative disease with symptoms that differs from other dementias. Commonly early symptoms in FTD are changes in personality and behavior, which can be interpreted as psychiatric disease. The delay in FTD diagnosis contributes to the burden of family caregivers. Therefore, it is important to have more knowledge about the pre-diagnostic stage. In this qualitative interview study, we explored fourteen family caregiver's experiences of the pre-diagnostic stage of frontotemporal dementia (FTD). Our findings suggest that the family caregivers experienced the pre-diagnostic stage of FTD as changes in the interpersonal relationship with their loved one. These changes were often subtle and difficult for family caregivers to explain to others. The findings from our study illuminate the importance of medical staff paying attention when a next of kin is concerned about subtle changes in a loved one. The findings also illuminate that awareness of FTD should be raised.

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Introduction

Dementia is an umbrella term for several diseases causing damaging, degenerative changes in the brain. The most common types of dementia are Alzheimer's disease (AD), vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (FTD).¹ Studies show that family caregivers experience the early stage of dementia as a complex phase of sense making and recognizing of early symptoms.²

Frontotemporal dementia (FTD) is a neurodegenerative disease that affects the frontal or temporal lobes in the brain, or both. These areas in the brain have important functions when it comes to behavior, planning, problem-solving, emotional control, and speech.³ FTD encompasses three clinical variants: a behavioral variant (bv-FTD) and two language variants: semantic dementia and progressive non-fluent aphasia.^{4, 5}

FTD accounts for 10% of all confirmed dementias in individuals with onset before 65 years.^{6, 7} It is most often diagnosed between the ages of 45 and 65, but it can also affect younger and older people.³ The average age of diagnosis is 57 years old.⁸ FTD is progressive and leads to death, on average about 80 months after caregivers notice

the first symptoms.⁹ There exists no cure for FTD today.¹⁰ The only treatment available is selective serotonin reuptake inhibitors (SSRIs) to relieve symptoms.⁷ Support for patients, families and caregivers is the most important interventions.¹⁰

The symptoms of FTD include personality changes, behavioral changes, and sometimes language deficits.¹¹ The symptoms are often accompanied by psychiatric symptoms, such as obsessions, mania, depression, compulsions and psychosis.¹² These symptoms are different from the memory deficits associated with more common types of dementia.^{3, 13} In addition, a gradual onset is one of the hallmarks of FTD^{14, 15} and the early symptoms are subtle and difficult to recognize for family caregivers.¹⁵ The symptoms often are interpreted by the family caregivers as variations in mood and personality,¹⁵ fatigue, stress, overwork, or depression.¹⁶ In addition, sometimes one of the first symptoms in FTD is lack of insight.¹⁵ An early frontotemporal diagnosis is important to achieve, but this often takes up to 5 years.⁷ The symptoms are often interpreted as neurological or psychiatric disorders by clinicians.^{17, 7}

Studies show that being a family caregiver to a person with FTD is particularly challenging and burdening¹³ because of the behavioral and personality changes, often young onset, and the delay in diagnosis.^{12, 18–21} Misdiagnosis or delay in correct diagnosis reduces the family caregivers' possibilities to seek supportive resources, support, and management.¹⁷

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FTD presents a diversity of symptoms and recognition and awareness of the earliest symptoms may contribute to earlier FTD diagnosis.¹² To our knowledge, no other qualitative studies have investigated the experiences of family caregivers of the pre-diagnostic stage of FTD. The knowledge of family caregiver's experiences would contribute to increased public, medical and nursing knowledge of FTD as well as its pre-diagnostic stage and symptoms. This may benefit to in earlier correct FTD diagnosis. The aim of our study was therefore to explore the family caregivers' experiences of the pre-diagnostic stage of FTD.

Materials and methods

Design

In order to achieve a deep understanding of how the family caregivers experienced their lives with their loved ones, we conducted a qualitative study in the Gadamerian hermeneutic tradition. Gadamer (1990) used the question "How is understanding possible?" to outline his philosophical hermeneutic theory. According to Gadamer (1993), all humans are part of history, and it is not possible to step outside history and look back at the past objectively. Understanding can only be possible with historical awareness; with historical awareness, everyone has a preunderstanding of the topic in question. Moreover, if preunderstandings are not recognized, there is a risk that understanding will be failed or meaning will be misjudged. The preunderstandings of the phenomenon should be visited time and time again and reflected upon during the process of gaining understanding.²²

Participants

The participants were recruited from two hospital psycho-geriatric units and one hospital neurological unit. The medical staff at the units was given written information about the study and was asked to inform actual participants (family caregivers of individuals with

FTD) about the study and ask if they were interested in participating. The inclusion criterion was a close relationship during the pre-diagnostic stage of FTD with a person later diagnosed with FTD. The participants returned the information letters to the main researcher with confirmation about interest in contributing to the study or with a refusal to participate in the study. The participants who wanted to contribute also added their phone numbers in the returned letter. In all, 16 persons were informed and agreed to participate in the study, but two of them could not participate for personal reasons. Fourteen people who were currently living or who had lived with a person with a diagnosis of FTD participated in the study. The participants had different relationships with the person with FTD and there was a variation in years past between observation of the earliest symptoms of FTD and the set FTD diagnosis (Table 1).

Interviews

The main researcher contacted the participants by phone after receiving the consent letters and the arrangements for the interviews were made in line with the participants' wishes. One interview took place at an office at a hospital, and one took place at a conference room at a hotel, but the rest of the interviews took place in the homes of the participants. The participants were interviewed by the main researcher and asked to narrate their experiences with the early stage of FTD. A semi-structured interview guide was used. This interview guide was developed for the study by the researchers, on the bases of literature review. The first question was: "Could you please tell me about the first time you experienced that your loved one had changed and what it meant to you?" with the following sub questions: "Could you please describe the changes?", "Could you please tell me more about your experience of the changes?", and "Could you please tell me what did the changes meant to you?" The interviews were estimated to last about 60 min, but they all lasted from 60 to 120 min. The participants were eager to tell their stories and had rich information, especially considering the initial question. All interviews were

Table 1
Participants and their loved ones.

Nr	Relationship to person with FTD	Gender of person with FTD	Age at earliest FTD symptoms observed in person with FTD	Age at FTD diagnosis in person with FTD	Years between observation of earliest symptom of FTD and FTD diagnosis
1	Daughter	M	55	67	12
2	Husband	F	45	47	2
3	Wife	M	65	69	4
4	Husband	F	67	67	0
5	Husband	F	64	67	3
6	Husband	F	61	64	3
7	Husband	F	45	55	10
8	Brother	F	65	70	5
9	Daughter	M	62	63	1
10	Wife	M	64	68	4
11	Wife	M	57	67	10
12	Close friend/former cohabitant	M	68	76	8
13	Daughter	M	66	70	4
14	Daughter	F	60	68	8
Relationships summarized					
	Husband				35.72
	Wife				21.43
	Close friend/cohabitant				7.14
	Siblings				7.14
	Child				28.57

Descriptions of participants' relationships to the persons with FTD. Descriptions of the loved ones with FTD: gender, age at earliest FTD symptoms, age at FTD diagnosis, and years between first symptoms and FTD diagnosis. Relationships summarized into percentages.

recorded and transcribed verbatim by the main researcher. The transcribed material was read through by all researchers in the study.

Ethical considerations

The participants were carefully informed that the interviews could trigger strong emotions that could emerge during or after the interview. If they needed support, they were told to contact the main researcher who is a registered nurse with specialization in psychiatry and several years of experience in psychiatric outdoor patients. The study was approved from the regional ethical committee in 2015 (ref. nr: REK midt 2015/847).

Text analysis

The four cyclical steps outlined by Fleming et al. (2002) inspired the analysis of the interview texts; (1): gain an understanding of the text as a whole, (2): identification of themes, (3): expanded understanding of the whole text and (4): Identification of passages.²² According to Gadamer, analysis of an interview text needs to follow the hermeneutic movement; from the whole to the part and back to the whole.²²

In the first step, the main researcher reflected upon her preunderstanding of the research question: how does family care givers experience the pre-diagnostic stage of FTD? The preunderstanding was that the family caregivers of persons with frontotemporal dementia do experience noticeable changes in their loved ones a long time before FTD has been diagnosed. All researchers separately read all the interviews as a whole text. The main researcher reviewed and wrote the fundamental meaning of the text as a whole, and this was read and reviewed by all the researchers.

In the second step, the main researcher gained an overall understanding of each text unit. Every sentence or section was investigated to expose its meaning in understanding of the research question. During this process, several meaning units were identified. The whole text and its meaning units were read by all the researchers and grouped into sub-themes. In the next stage, a main theme was made based upon the sub-themes. The sub-themes were reflected upon in the light of the main researcher's preunderstandings. Every section or sentence was then related to the meaning of the whole text, which expanded the sense of the text as a whole. The final step involved identifying passages that seemed to be representative of the shared understandings of the participants and the researcher. This multistep process was carried out several times during the analysis. The participants' perspectives were represented in the text as clearly and closely as possible and direct quotations were included.

Results

The main theme in our study was that the participants experienced the pre-diagnostic stage of FTD as a process with different steps of changes in the relationship with the loved one. This main theme was built upon the following subthemes: (a) becoming distant, (b) becoming insecure, (c) becoming devastated and (d) becoming a stranger. These steps of changes did not always occur in the same order in the participants.

Becoming distant

The process of changes in the interpersonal relationship with their loved one most often started with an experience of distance. An interpersonal relationship in this study is understood as a strong, deep, or close association between two or more people. In this study, the context of an interpersonal relationship was mainly intimate

relationships (marital or romantic), but also family relationships like parent-child and sibling.

At first, the participants usually started experiencing almost unnoticeable changes in the relationship with their loved one, often in the form of increasing silence and apathy. The silence and apathy especially contributed to the experience of disconnection and distance in the relationship. Their loved one could seem uninterested in daily conversations, get more easily offended or irritated, or be more silent than usual. "He changed in the way he responded to me... he got easily offended and seemed agitated and a bit paranoid." This feeling of disconnection in the relationship resulted in irritation or a subtle feeling that something didn't feel right. "We (the family members) were wondering about her, if there really was something wrong with her. She sometimes seemed disoriented, her personality changed, and she became so silent."

These changes were not interpreted as a symptom of disease but rather often understood as due to natural causes, such as part of an aging process, stress, or just a downturn period in the relationship. "He did not take part in conversations like he used to, he did not have any input, and he withdrew. But we thought this was because he had bad hearing and did not manage to follow the conversation. I thought he was just getting old."

The changes could also be experienced as recognizable symptoms from earlier periods of psychiatric or somatic illness. "She had periods of depression and fatigue earlier in her life, and I sometimes wonder if the frontotemporal dementia started already then."

Becoming insecure

For most of the participants, the experience of distance gradually blended into an experience of insecurity about the situation. The changes in their loved one gradually became more noticeable, with he or she losing personal abilities or lessening personal activities, such as being active and social and losing interest in hobbies and even family. The participants found this strange, frightening, and irritating. Still, the changes were difficult to pinpoint and explain to others, and several participants also felt ashamed about the behavior of their loved one. Many of the participants talked to close friends or other family members about their concerns. Often, the affected person did not see the changes in himself or herself, which made it difficult to talk about it and also to make the person go see a doctor. This resulted in insecurity about the situation. "So I talked to my own doctor. I tried to explain the symptoms, and the doctor asked if we had problems in our marriage. I told him no and tried to explain a bit more, but I found it kind of embarrassing. I started to wonder if I was exaggerating. Nothing came of the visit to the doctor."

Some of the participants experienced denial. In retrospect, they see that they subconsciously understood that something was wrong, but they tried to avoid thinking about it or talking about it with their loved one. "At first I didn't take any action, because I didn't want anything to be wrong with her. I don't know. I was in denial. I knew something was wrong, but I didn't know what it was. Maybe it was wrong of me. I have struggled with guilt. Could I have done anything? Could this have been avoided? Should I have seen something earlier? Should I have taken action earlier?"

Becoming devastated

As the helplessness of the loved one increased, the participants felt increasingly worried about the safety of their loved one. For a few of the participants, being devastated was their first step in the process of losing their loved one, as this was their first experience of changes in their loved one. This was particularly the case for the participants who experienced only a few years between observation of the earliest symptom of FTD and a set FTD diagnosis. A loss in ability of taking

care of oneself was commonly seen, particularly in personal hygiene. Even if the loved one had been neat and tidy earlier, it did not seem important to take a shower anymore. In some cases, the participants had to force their loved one to take a shower, which resulted in conflict and feelings of guilt. This was a devastating and exhausting situation. The participants who did not live with the person with FTD experienced that their loved one looked sloppy and unkempt when they came at visit. There were often clear signs of a lack of self-maintenance, such as overgrown nails and hair, rotten teeth, and bruises. In some cases, the participants also experienced their loved one wandering around outdoors or not being possible to get in touch with the person for longer periods of time. This led to feelings of concern, helplessness, and devastation in the participants. They also experienced a lack of help from health services because the person with FTD refused to receive assistance or left the house before health services came to visit. "The house started to decline. . . He did not clean. It smelled horrible inside the house. He did not turn the stove on, it was freezing cold, and he had no lights on. The community care tried to help him at first, but he was so aggressive toward them. I was worried sick; it was exhausting."

Several dangerous situations emerged because of the person's loss of abilities, such as driving, which became hazardous. The loss of skills and functions regarding cooking also led to potentially dangerous situations, such as fire or food poisoning. The participants experienced these dangerous situations with irritation, fear, and sometimes anger. In the wake of these situations, the participants were worried that it would happen again, which triggered catastrophic thoughts and insomnia. The participants struggled with leaving their loved one home alone when they went to work, which resulted in taking sick leave from work and sometimes even early retirement.

Some participants experienced serious behavioral and personality changes in their loved one, such as inappropriate laughter, sexualized behavior, jealousy, anger, physical abduction, shoplifting, abuse of alcohol, and wasteful spending. It was devastating to when their loved one, who had been modest and patient, suddenly became aggressive and abusive. Their loved one's behavioral and personality changes led to disgust, concern, irritation, fear, confusion, frustration, guilt, and catastrophic thoughts in the participants. "My wife and I were traveling. She got so depressed; she was not herself. Suddenly, I noticed that she drank alcohol in secret and that she had stolen alcohol from the tax-free shop."

Becoming a stranger

The last step in the process of the pre-diagnostic stage of FTD was the experience of becoming a stranger in the relationship. The loved one became a stranger due to these changes in behavior and personality and took on a different role in the relationship. The participants experienced that their loved one, once a person with interests, hobbies, and very good skills in everyday living, had lost an important part of themselves, the part that constituted them as a person. Several participants felt like they were living with a complete stranger. This was a devastating and horrible experience for the participants and resulted in tremendous feelings of guilt. As the person with FTD started to change and became increasingly helpless, the participants were forced to take on a new role in the relationship: a caregiver role. "I could not use him as a conversation partner anymore because he didn't understand in what way he could help me when I was struggling with something. It is a completely different relationship."

The role of caregiver was described as burdening by the participants. Some of the participants had to take on a parental role for their parent. "My mother lost her love and care for me. She was rude to me and made fun of me. It was horrible. You kind of expect your mother to feel love for you your whole life. Instead I had to be the parent for my mother."

This burden resulted in exhaustion and sometimes led to depression. The loved one had no insight in the fact that he or she had undergone changes in personality or behavior and did not want to talk about it at all or became irritated or angry if the participant tried to talk about it. "If I tried to confront her with her shoplifting and drinking, she just got angry with me. She said I was mean. She denied everything. I found it awful. It was horrible." In some cases, a need to have space between the person with FTD and the participant emerged even if the relationship had been positive and close earlier. This created conflicting feelings due to the need for space on one hand and a sense of duty on the other hand.

Discussion

The aim of this study was to explore the family caregivers' experiences of the pre-diagnostic stage of FTD.

The participations in our study described the early stage of frontotemporal dementia as changes in their interpersonal relationship with the loved person, because of personal and behavioral changes. It was experienced as a complex and demanding situation, characterized by the emotions of shame, irritation, guilt, exhaustion, and fear. The early changes were subtle and often misinterpreted or denied by the family caregivers and were difficult to explain.

As far as we know, only one study has explored family caregivers' experiences of the pre-diagnostic stage of FTD.¹⁵ However, studies argue that the most difficult period for the family caregiver of a person with dementia is the period before the dementia diagnosis. The changes in personality and communication are difficult to handle, and the caregivers do not have an explanation for these changes. The changes in marital roles are particularly distressing.²³ During this period, the doubt is often followed with hope that the changes would pass or some natural explanation would emerge.²⁴ This is in line with the findings in our study, where the participants first experienced almost unnoticeable changes in the communication and relation with their loved ones. Later on, as these changes got more noticeable, the participants felt insecure about the situation and sometimes went in denial.

A study of Massimo et al. (2013) shows that the relationship in spouses often undergo a sudden shift in FTD, as a result of loss of meaningful connection with the spouse.¹³ Our study shows a more gradual change in the relationship. The first changes described under "becoming distant" did result in irritation but was explained by the participants as due to natural changes such as part of an aging process, stress, or just a downturn period in the relationship.

In FTD, changes in the patient's behavior and changes in the interpersonal relationship between the spouse and the caregiver is associated with caregiver depression²¹ and is challenging for maintaining a healthy marital bond.²⁵ The behavioral changes leads to an absence of meaningful connection to the loved one and may create feelings of isolation and anger.¹³ This is recognizable from our study, in the findings "becoming devastated". As the behavioral and personality changes in the loved one became more noticeable and serious, the participant described disgust, concern, irritation, fear, confusion, frustration, guilt, and catastrophic thoughts.

Caregivers often experience loss of self-identity and the role changes in the relationship in FTD.¹³ This is in line of findings in our study. The participant describes the experience of "becoming a stranger" in the relationship with their loved one. Several participants felt as if they lived with a total stranger. Their loved one had lost their personality and what once constituted them as a person. The roles of being a spouse, child, close friend or sibling changed into being a caregiver as the loved one changed and needed more support in the everyday life.

Studies show that family caregivers in early onset dementia get concerned about the changing roles in the family as the dementia

progress.^{13, 16} and that adult children experience that the main caregiver (mother or father) avoids or withdraws from the situation.²⁶ Spouses and child caregivers may experience similar levels of burden.²⁷ Four of the participants in our study were grown up daughters of a loved one with FTD. These participants experienced that they had to take on a parental role for their parent, which was demanding and distressing.

In our study, the family caregivers did not interpret the early signs of FTD as signs of a dementia disease. This is in line with other studies which shows that in the early stage of FTD, the symptoms might lead to a misdiagnosis of depression,¹⁹ midlife crisis, marital conflict, stress, menopause,⁵ manic psychosis, obsessive-compulsive disorder, or sociopathic personality disorder.²⁸ The most frequent misdiagnosis of bv-FTD is major depression, where the family caregivers have interpreted the apathy, loss of interest, and social withdrawal as depression.¹¹ Some of the participants in our study tried to explain the symptoms to medical staff, but did not feel as if it was taken serious. Studies show that this is not uncommon. Physicians may be unaware that neurodegenerative disease can affect younger persons. This leave the family caregivers in a frustrating, uncertain, and confusing situation.²⁸ Also, it is not unusual for couples to seek family counseling or divorce during the pre-diagnostic stage of FTD.²⁸ Several participants in our study experienced lack of insight in their loved ones. Most of the patients with FTD do not complain of any symptoms, behavioral changes described by family caregivers are often unspecific, the patients may perform normally on neuropsychological tests, and structural imaging abnormalities may be subtle.¹¹

Blandin and Pepin (2016) have developed a theoretical model of pre-death grief in dementia caregivers. The model encompasses three states: (1) the separation state, (2) the liminal state, and (3) the re-emergence state.²⁹ The separation state is characterized by the losses that a family caregiver experiences in their loved. It is difficult to acknowledge the loss, as the family caregiver may not recognize the changes, may resist or deny the changes, or be too emotionally drained to see the changes.²⁹ Our study supports these findings, which describes both loss of emotional connection with the loved one and a denial of changes in the participants. The liminal state is characterized by being in between a previous situation and an emerging situation. It encompasses an experience of ambiguous loss and recession of the known self, which precedes physical death.²⁹ In the findings of our study, this state appears in the subthemes of becoming devastated and becoming a stranger. According to Blandin and Pepin (2016), tolerating the painful emotions in this state enables the grief process to unfold, and there is an opportunity to adapt to the new, emergent situation. This naturally moves the caregivers into the final state of the grief model: the state of re-emergence. In this state, it is possible for the family caregiver to adapt to the new life situation and to the reality of the loss. In general, during the grief process, adaption is a goal that signals resolution.²⁹ However, the participants in our study remained in the painful liminal state for up to 12 years before they learned the actual diagnosis.

This may constitute the biggest difference between the pre-diagnostic stage of FTD and other dementias: a delay of diagnosis and a delay of the state of re-emergence.

Methodological consideration

The design of our study made us able to gain a deeper understanding in a less-explored subject: family caregiver's experiences during the pre-diagnostic stage of FTD. The participants experienced the pre-diagnostic stage of FTD as a process with different steps of changes in the relationship with the loved one. The participants experienced these steps in different order.

The participants had different relationships with the person with FTD and they all were in different stages in a mourning process

during the interviews. The differences in relationships and the age of the participants may have contributed to different experiences during the pre-diagnostic stage of FTD. Some of the participants were still living with their loved one, some of the participants had experienced the death of their loved ones, and, in some cases, the loved one had moved to an institution. This may be the reason why the participants experienced the different steps in the process in a different order.

All participants were emotionally affected by their loss during the interviews. This may have influenced their narratives, leading their focus to the present situation of their loved ones or the mourning process, instead of the early signs of disease. However, each interview was rich in details on early signs of FTD and the participants' experiences of it.

This interpretation is only one of several possible ones. The findings in our qualitative study cannot be generalized in a statistical sense, but we argue that they are transferable to other family caregivers of persons with FTD. This study can be used for development of competence regarding early signs of FTD and development of competence regarding the difficult and complex task of early and correct FTD diagnosis.

Conclusion

The family caregivers in our study experienced changes in their loved one before actual diagnosis. The changes were not initially interpreted as signs of disease, but eventually, these changes led to major concerns. Still, the changes were difficult to pinpoint and describe to others. The devastating and exhausting character of the process, the difficulties of describing the subtle symptoms and a lack of awareness in clinicians may contribute to the delay in diagnosis. In other dementias, like Alzheimer's disease and vascular dementia, the symptom of memory loss often raises the suspicion of dementia. In these cases, the family caregivers may be prepared for a dementia diagnosis, and the symptoms may be easier to explain to a clinician. Our study shows that is important for clinicians to be pay attention when spouses or other family members are concerned about personality and behavioral changes or loss of functions in a loved one, even if the symptoms are difficult to pinpoint and describe. The awareness of frontotemporal dementia should be raised, especially among general clinicians, but also among specialists.

Conflicts of interest and funding

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