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Caring for loved ones with frontotemporal degeneration: The lived experiences of spouses

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Abstract

There is an abundant literature about the experience of caregiving for a spouse living with Alzheimer's disease (AD), but there are very few qualitative studies about caregiving for persons living with Frontotemporal Degeneration (FTD). FTD causes a change in personality and affected persons may lose the ability to adhere to social norms. Thus, the emotional loss caregivers experience is often confounded by anger in response to embarrassing and socially inappropriate behaviors. In this paper, we offer a glimpse of this lived experience through the voices of two spouses whom we interviewed, each with experience caring for persons living with FTD. We suggest that FTD caregivers experience a loss of emotional attachment to their spouse because of their partner's behavioral symptoms. This loss gives rise to feelings of isolation and anger as caregivers assume new roles and reimagine their future. The findings from these interviews illuminate the need for more research and greater attention and support for FTD caregivers early in the disease trajectory.

Keywords

Frontotemporal degeneration; Caregiver; Behavior

1. Introduction

An abundant literature focusing on the impact of caring for a person living with dementia highlights sources of caregiver burden and stress. Comparative descriptions of the particular challenges posed by different types of dementia are still scant, and most of the dementia caregiving literature focuses on Alzheimer's disease (AD)—by far the most prevalent of the neurodegenerative diseases. Frontotemporal Degeneration (FTD) is a common cause of early-onset neurodegenerative disease.¹ FTD is progressive and leads to death, on average, about 80 months from the time that symptoms are first noticed by caregivers.² Changes in the frontal lobe are associated with an early change in personality including loss of insight into personal behavior, emotional indifference and diminished concern for social norms.³ In fact, at the time of initial evaluation, over 75% of persons living with FTD display behavioral symptoms such as apathy and disinhibition.⁴ Studies have consistently

demonstrated higher levels of caregiver distress, burden and depression in FTD caregivers when compared to AD caregivers.^{5–8} This is likely related to several factors including the much younger age at which the disorder appears (average age 60 at onset),⁹ behavioral changes that are severe and appear early in the disease process and the limited resources available to this unique group.^{10,11} As experienced socially, the behavioral symptoms in FTD are qualitatively distinct from those associated with a dementia that causes primarily memory difficulty, but there are very few qualitative studies describing the impact of these behaviors on caregivers. The purposes of the interviews described here were to begin to explore spouses' perceived experiences of and responses to living with a person with FTD. In doing so, we sought to reveal caregivers' stressful incidents, articulated meanings, and strategies used to cope with behaviors that are common in FTD.

2. Background

FTD is characterized by behaviors that are disruptive to relational connection and communication.¹² For example, disinhibited behaviors may include inappropriate conversations with complete strangers on unsuitable topics, excessive spending and compulsive overeating, including intake of unusual non-food items.⁴ Some affected individuals may display a profound apathy that leads to urinary or fecal incontinence when s/he lacks motivation to use the bathroom—even when physically able to do so.¹³ These behaviors are very common in the FTD patient population, and are strongly associated with increased caregiver burden and stress.^{7,14} A questionnaire-based study of FTD spousal caregivers demonstrated that passive behavior, notably apathy, had the most impact on the deterioration of the marital relationship.¹² In combination, the personality changes and behavioral symptoms impact the closeness in the relationship; thus, the bond between caregiver and care recipient that sustains caregiving, even under adverse conditions, is, in effect, severed.¹⁵

Most of the dementia caregiving literature focuses on caring for persons with AD, but caregivers of persons living with FTD face a set of unique challenges. Persons with AD are older, show signs of cognitive impairment early in the disease process and tend to have relative sparing of personality until later in their disease course.¹⁶ In contrast, persons living with FTD are relatively young and many are still working and raising children.¹⁷ Furthermore, persons living with FTD demonstrate prominent and unusual behaviors early in the disease, prior to deterioration in cognitive function. This is presumably the reason for poor caregiver outcomes in the FTD caregiver group, as prior research has demonstrated a relationship between behavioral symptoms and high levels of burden in FTD caregivers.¹⁰ These caregivers also face the additional challenge of the lack of public awareness and appropriate resources.¹⁷ Public understanding of dementia is largely based on knowledge about AD. FTD caregivers are often inappropriately referred to resources developed for caregivers of persons with AD.¹³ Not surprisingly, then, caregivers of persons living with FTD are less satisfied than their AD counterparts with the information they are given about the disease and with the availability of health care services.¹⁸ Support is essential to maintain the well-being of the caregiver.¹⁹ To achieve this, we must better understand the impact of behavioral symptoms on the caregiving experience. While a beginning literature on burden in this population is evolving, caregivers' interpretation of the meanings of behavioral symptoms is a particularly challenging variable that has not been well examined. Assignment of meaning may impact caregivers' responses, both behavioral and emotional, to the person living with FTD. Thus, an investigation of caregivers' experiences caring for a spouse living with FTD that includes assignment of meaning will help fill a gap in this area.

3. Methods

3.1. Participants

Wives of two persons diagnosed with probable FTD who were established patients at a specialty cognitive neurology clinic in a large university health care setting agreed to be interviewed. The wives^c represented the typical demographic profile of FTD caregivers: female gender, young age, high educational level.⁷ Their spouses living with FTD ranged in age from mid 50s to early 60s and their education ranged from some college to graduate education. Both persons living with FTD scored in the mild range of cognitive impairment (>23) on the MMSE (29/30, 27/30) and their disease duration was less than 2 years. Further, both spouses displayed several behavioral symptoms that are presumed challenging to family caregivers.

3.2. Interview

Using an investigator-developed guide, audio taped 60-min interviews in the form of a conversation were conducted in the spouses' homes by the first author. The aim of the conversation was to enable the caregiver to give an account of caring for her spouse with FTD. The general questions that framed each interview, followed by specific probing, included:

- How did you first understand the diagnosis of FTD?
- What does the diagnosis of FTD mean for you now?
- Are there certain behaviors that are difficult for you to manage?
- What has been most difficult for you as a caregiver?
- What does a good day look like for you?

3.3. Interview analysis

Interviews were audio recorded, transcribed, and checked for accuracy by the first author and then entered into Atlas.ti 6 (Scientific Software Development, Berlin) for ease in coding and theme development, guided by Benner's interpretive phenomenological methods.²⁰ In Interpretative Phenomenology, the researchers' assumptions and pre-understandings are made as explicit as possible prior to the study, and then any "hidden" assumptions, not recognized prior to the study, are carefully articulated as they show up in the data analysis. The research goal is to convey the knowledge, meanings, habits and practices that participant caregivers disclose in their first person experience-near narratives. Thus, we began by reading the entire interview to get a sense of the overall context of the caregiver's situation. Interpretive notes were written during and after each reading of each interview. Themes identified in the interviews were agreed upon by two of the authors (LM and PB). The themes with exemplars and commentary below reveal the lived experience of these two FTD caregivers.

4. Findings

4.1. Identity and role change

Self-identity is defined by commitments and identifications in the frame in which we determine what is good or valuable.²¹ Persons living with FTD have a reduced capacity to determine what is good or valuable because of their loss of social and emotional perceptual capacities.²² Their previous identity is lost and a new orientation to the world must be

^cSpecific details were modified to protect the privacy of the participants.

established; the caregiver must do most of this work of rebuilding some semblance of a shared social world. In the process of caring for a person living with FTD, there is a relatively sudden shift in the way spouses view their partner and their spousal relationship.²³ Of necessity, but often with resistance, spouses begin to take on new roles and responsibilities. Part of their new identity is special knowledge and skill as a caregiver.²⁴ This role change can be difficult for spouses as there may be, many disruptions to daily life. The next passage describes the impact of caregiving on the identities of the wives.

All of a sudden I went from wife to caregiver. And that label was put on my chest that said 'caregiver now.' And then I accepted it for a little while and then I realized that 'I don't want to be your caregiver.' I really don't want to do that. (Caregiver 1).

Most of the time I am sad because I hate the change. I hate that we are going through this and we have to change our entire lives and everything about them. Nothing is the same. (Caregiver 2).

The diagnosis of FTD represented a life-changing event for the family. The former identities as husband and wife were lost, disrupting past self-defining relationships and relational experiences. The loss of shared meanings and roles of the past were major sources of loss for these two women caring for their now dependent partners.

4.2. Isolation

The behavioral changes that occurred were distressing to the caregiver, in part because the lack of insight by the person living with FTD heightened the caregivers' sense of the loss of meaning and connection to their spouse. The absence of a meaningful connection created feelings of isolation, separation, and alienation from the person living with FTD.

I think what has been the hardest for me is that he doesn't want to talk about it to me. So, it's sort of the elephant in the room. He hasn't wondered how it has affected me. (Caregiver 1).

I never expected to be by myself... All these changes in our lives by myself... Not having someone to talk to... Not having someone to talk things over with. That is the hardest part. (Caregiver 2).

This kind of social isolation and loss of shared understandings and feelings of not being in the 'same or shared situation' are perhaps understandable in light of the emotional and cognitive losses associated with FTD.

4.3. Anger

The feeling most often expressed by both caregivers in response to the behavior of the person living with FTD was that of anger. Anger is an emotion that is triggered by a threatened or actual violation or disruption of social norms and relational expectations.²⁵ Caregiver 2 describes an example of how her husband abandoned usual social conventions.

He works in a school and he said something inappropriate to a student. He asked a 16 year old if she was pregnant! And you just don't do that in a school! (Caregiver 2).

In a second passage, she describes her reaction to another common behavior in FTD—a lack of empathy.

He doesn't say goodbye. And doesn't kiss anybody or hug anybody anymore. Even with friends or family. If someone dies or is ill, he has no feeling. It's terrible! You want to tear your hair out!! (Caregiver 1).

Although caregivers continued to convey feelings of love for their spouse, and still wanted to share those feelings with their spouses, they also questioned why their emotions were not reciprocated. It is important to note that persons living with FTD have a diminished capacity to empathize or sympathize with their loved ones,²⁶ a loss that may generate even more anger in the partner. Impaired ability to perceive emotional meanings, moods, and social climates, often results in non-responsive behavior and disconnection which are likely to precipitate anger over the infringement of boundaries, meanings, and social entitlements.

We're mad at him a lot of the times 'cause I just can't believe... It doesn't seem like he is trying. I am, like, angry all the time. You feel like, ugh, I am wasting my time. I should be, like..., but he doesn't care. I could scream and holler and throw things and he doesn't care. So it's not like I am hurting him. It's like I am venting for myself. (Caregiver 2)

The lack of emotional responsiveness is perceived by the caregivers as “inconsiderate” and “non-caring.” When former normative relational exchange and appreciation decline, the caregiver commonly experiences the social response of anger.²⁷ Relational norms break down as the past patterns of reciprocation and appreciation erode, and the glue of emotional connection evaporates. In other words, what has been most sustaining and human in a mutual relationship is increasingly diminished related to the affected person's cognitive inability to ‘read’ emotions and meanings in situations and respond empathically.

4.4. Facing the future

The diagnosis of FTD rather quickly forces spouses into new meanings and self-understandings. For example, in order to look toward the future, caregivers have to radically reinterpret their expectations of that future. Even the notion of a ‘good day’ seems too much to hope for; spouses limited their descriptions to unlikely occurrences, i.e., “vacation with nothing to do” (Caregiver 1) or “a very productive day” (Caregiver 2). And, in this next example, a caregiver describes having to come to terms with the possibility of managing the family farm alone.

I don't know if I can do this farm by myself. So it has been very emotional this past year. Sunday night, perfect situation: Someone called to take the horse because I don't know if I would be able to take care of it myself. I cried for hours. (Caregiver 2).

Although spousal CGs may overlook some of the new behaviors, it is nonetheless very difficult to accept the overall changes in their loved one. This caregiver talks about the hope she has for her husband, which is that he learn that he still has assets aside from his intelligence.

He has always relied on his brain that he has used all his life. And that is one of the lessons I am hoping he learns. That there is more to him than his brains. (Caregiver 1).

4.5. Reframing

The devastating impact of the diagnosis of dementia challenges all caregivers to cope with the psychological experience of caregiving. FTD caregivers are faced with additional demands related to coping with the social meanings of the behaviors most common in FTD (e.g., apathy). In order to cope with her husband's passive symptoms, Caregiver 1 separates the disease from the person and tries to reduce her interpretation of his behavior to the neuronal level. But even such an accurate perception of the pathology involved cannot erase the blunted social-emotional responses.

I have learned that is the disease. I've got that. That is not him. I can almost picture the neurons not being able to, you know, connect. I can just see them physically. (Caregiver 1).

Knowing that their spouses were losing functional capacity, caregivers adjusted their expectations. In order to cope with the husband's apathy and inertia, Caregiver 1 excuses her husband from some obligations.

I don't have as many expectations for him. If he does or doesn't do something. I don't make a big deal about it. You know, like a hall pass. (Caregiver 1).

Caregiver 2 describes her frustrations with her husband's blunted emotions. She copes by removing the blame from her husband. In this passage we see that she starts to understand his decreased capacity to react.

Does he not care or can he just not react to it? You know, somewhere inside of him, does he understand, but just can't react to it anymore? (Caregiver 2).

Although the caregivers are somewhat comforted by identifying the symptoms as part of the disease, they are nonetheless still connected to their spouse as a person. FTD challenges core issues of being human. The behavioral manifestations of FTD have social meanings that create surprise and anger over the loss of the affected spouse's ability to respond appropriately to these shared meanings about death, fatigue, sadness, loss and so on. Thus, every caregiver must find a way to understand and cope with the "thankless," non-reciprocated, unappreciated tasks of caregiving. This creates a tension and paradox regarding the loss of shared relational identity with the affected person... the more the caregiver decontextualizes and understands scientifically the husband's losses, the less the caregiver will be able to accord the same respect and sense of connection with him that she had known before the onset of FTD. Because each social situation calls forth the need to make sense of her loss, the caregiver enters such situations with the task of choosing whether to reinterpret and explain the spouses' lack of appropriate responses as brain-based, rather than as character- and person-based.

5. Discussion

The two caregivers interviewed here expressed emotional reactions to the person with FTD who has impaired emotional-relational capacities that support and sustain caregiving, including emotional recognition of the other. This loss gave rise to caregiver feelings of isolation and anger. Although themes such as isolation have been reported in AD caregivers,²⁸ FTD caregivers also experience anger related to their spouses' socially inappropriate and embarrassing behaviors coupled with their sustained disinterest and lack of usual emotional responses to meaningful events or to the caregiver's emotional responses. This is even more difficult to bear because the general public are conditioned to behaviors in older persons with AD and are not so accepting of inappropriate social situations in the young old population.

Caring for an individual living with FTD presents unique challenges early in the disease process, including decline and eventual loss of the very emotional capacities and social reciprocities²² that ordinarily sustain caregiving relationships. Behavioral symptoms such as apathy seriously limit the ability of the person living with FTD to engage in meaningful relationships that recognize the emotional experience of the self and others. Although apathy is present in other dementias such as AD, the severity of the behavior is at a much greater degree in persons living with FTD.¹⁰ Further, such behavioral changes are severe early in the disease course, a time when caregivers are simply trying to cope with the diagnosis of a fatal illness. Because of the patient's greatly reduced capacity to experience empathy—a very early sign—reciprocal role identities and shared emotional-relational capacities are lost

for both affected person and spouse. In contrast, persons living with AD do not show significant changes in empathy.²⁹ Indeed, previous research has shown that caring for persons living with FTD differ significantly from caring for persons with other types of dementia, like AD.³⁰ A recent qualitative study of FTD relatives described socially embarrassing behaviors and associated stigma as difficult for FTD caregivers.³¹ The interviews described here suggest that, in comparison with caregivers of persons with other dementias that cause primarily cognitive changes, FTD caregivers may face distinctly different caregiving challenges. Such challenges are due to the patients' impaired emotional responsiveness and loss of the ability to connect with others. These losses are challenging and profound, undermining the very meanings of informal caregiving.

5.1. Limitations

The sole perspectives of two female spouses from one geographic, urban region limit generalizability of these findings, as does the exclusive focus on their common experiences or themes. Yet, the information gathered through these two in-depth interviews contribute evidence to suggest that FTD caregivers' experiences are likely different from those of caregivers of persons living with other dementing illnesses. Clearly, more research is needed to validate and further expand these findings. With a larger sample, attention to both shared and individualized perspectives can be elucidated. Particular attention should be paid to understanding caregivers' interpretations and reactions to "socially unacceptable" behavioral expressions, using narrative reports to elucidate the complex nature of their experience.

6. Conclusions

The findings from two interviews suggest that FTD caregivers experience a profound sense of loss—of previous identity, of marital connections, of shared 'taken for granted' social meanings and of the prospect for a shared meaningful future. Under any circumstances, caregiving is a complex psychological experience, compounded by the particular symptoms displayed when one partner is living with FTD. Greater understanding of behavioral interpretations and associated emotional responses could contribute to a more complete picture of the caregiving experience for these couples, especially when anger and disruption of emotional attachment and connection are each significant sources of burden.³² Such qualitative descriptions of the meanings of the anger and loss experienced by caregivers of persons living with FTD could be used to help caregivers reframe emotionally laden and meaningful events. Special attention and support should be offered to FTD caregivers early in the disease process to identify coping strategies, provide alternate interpretations and facilitate articulation of the loss of shared meanings and emotional capacities between caregivers and persons living with FTD. It may be possible to support FTD caregivers by actively listening to their expressions of the emotional and socially situated losses that come with their partner's reduced capacity to perceive emotions, and, thus, 'read' social situations. Diminishing caregivers' sense of anger related to social behaviors, while supporting their connection to the person-hood of the afflicted partner, is an ongoing challenge for caregivers and their providers who wish to help. Research on the effectiveness of interventions, such as strategies to enhance caregivers' understanding of the partners' lost capacities, may inform services for this high-risk population.

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