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Sources of Stress for Family Members of Nursing Home Residents with Advanced Dementia

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Abstract

The sources of stress for families of nursing home (NH) residents with advanced dementia have not been well described. Semi-structured interviews were conducted with 16 family members previously enrolled in the Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study, a prospective cohort of 323 NH residents with advanced dementia and their family members. Questions inquired about the experience of having a family member in the NH, communication with health care professionals, surrogate decision-making, emotional distress and recommendations for improvement in care. Transcripts were analyzed using the constant comparative method. The majority of participants were female (63%), children of the resident (94%) and white (94%). The average age was 62 years. Four themes emerged: 1) inadequate resident personal care, resulting in family member vigilance and participation in care; 2) stress at the time of NH admission; 3) lack of communication with NH physicians; and 4) challenges of surrogate decision making, including the need for education to support advance care planning and end-of-life decisions. Our results support the provision of emotional support to families upon resident admission, education regarding prognosis to guide decision making, improved resident care and greater communication with health care professionals.

Keywords

caregivers; long-term care; Alzheimer's disease

INTRODUCTION

Currently, an estimated 5 million individuals in the US suffer with dementia, a number expected to increase to 13 million by 2030.¹ Nursing homes (NHs) play an important role in the care of patients with dementia; up to 90% will be cared for in a NH,² and as many as 70% will die in this setting.³ Although NHs are a common site of death for persons with dementia,⁴ end-of-life care provided in this setting is not optimal.^{5–6}

High quality end-of-life care is both patient and family-centered,^{7–8} and includes the provision of comfort to patients, emotional support to families and support for shared decision-making. Unfortunately, families of NH residents often report inadequacies in

patient care, physician communication and emotional support.^{9–12} Family member dissatisfaction with end-of-life care is greater in the NH than in home or hospital settings.⁹

Little research has focused specifically on family members' concerns regarding end-of-life care for NH residents with advanced dementia. Such inquiry is warranted due to the unique features of dementia including the prolonged course of illness, intensity of care required, presence of behavioral disturbances and the unique challenges of shared decision-making. Medical decisions for patients with advanced dementia are particularly difficult due to the paucity of high quality outcome data, challenges with prognostication,¹³ the failure to recognize dementia as a terminal illness⁶ and the inability to elicit patient preferences.

Family members of patients with dementia are at risk for depression and anxiety, even when care is provided in a NH.¹⁴ However, the sources of emotional stress in the NH environment which may contribute to this risk have not been fully described. Prior work has documented that families experience distress due to the logistical challenges of visitation and the difficulties of end-of-life surrogate decision-making.¹⁵ Using a follow-up qualitative design, this study investigated sources of stress among family members of NH patients with advanced dementia who had participated in a larger quantitative study, and sought to obtain suggestions for improving the quality of care provided to this vulnerable population.

METHODS

Study Design

This qualitative study follows a larger quantitative study in a sequential mixed methods design.¹⁶ All participants were previously enrolled in the Choices, Attitudes and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study,¹⁷ a prospective cohort study of nursing home residents with advanced dementia and their health care proxies (HCPs). The CASCADE study was designed to investigate the natural history of end-stage dementia including patient and HCP outcomes. Details of the methodology are described elsewhere.¹⁷ Briefly, residents were from 22 NHs within 60 miles of Boston, were over 60 years of age and had advanced dementia (could not recognize family, had minimal verbal communication, total functional dependence, incontinence of urine and stool and inability to ambulate independently), and all residents had a HCP who could provide informed consent and communicate in English. The institutional review board of Hebrew SeniorLife approved this study and all participants provided written informed consent.

Participants

Participants in this report included HCPs of NH residents with advanced dementia who were enrolled in the original CASCADE study. Data collection for the CASCADE study took place from February 1, 2003 to February 28, 2009. Potential participants for the present study were contacted beginning on January 14, 2010. Eligibility criteria included: 1. the HCP was a family member of the resident (95%); 2. the resident was either alive in the NH on January 14, 2010 or had died in the prior year (between January 15, 2009 and January 14, 2010); and 3. the HCP had completed the CASCADE study and was able to be contacted. Family members of residents who had died prior to January 15, 2009 were excluded due to concerns regarding adequate recall of events. Screening information regarding resident vital status and current residence in the NH was obtained from each NH by a research assistant prior to subject enrollment.

Data collection

The objective of this study was to further understand the sources of stress for family members of NH patients with advanced dementia. Semi-structured interview questions were

developed based on *a priori* hypotheses of general categories of questions, generated from literature review and results of quantitative analysis of the CASCADE data.^{18–20} These categories were as follows: 1. the family members' overall experience in the NH; 2. communication with NH health care professionals; 3. challenges of surrogate decision-making; 4. sources of emotional distress; and 5. recommendations for improvement of NH care (Table 1). A trained research assistant conducted telephone interviews lasting 19 to 123 minutes (average 50 minutes). Generic probes such as “can you tell me more about that” were used as needed during the interviews.

Analysis

Interviews were audio taped and transcribed by a professional transcription service. Transcripts were checked for accuracy against the audiotapes prior to entry into NVivo 8, a qualitative software package (QSR International, Melbourne, Australia). Two researchers (JGL, RPL) coded the transcripts using the constant comparative method,²¹ in which original themes are revised to reflect new themes generated during the coding process. Initially, broad codes were developed to reflect thematic categories of the interview guide. Each researcher then generated finer themes within these codes and themes were compared and reconciled as needed. Reliability between the researchers as to how transcript text was assigned to themes was established at 80% or greater agreement. Matrices were used to aggregate the data elements, and overarching themes and subthemes were then developed and compared across transcripts to ensure that they were both representative and inclusive.

RESULTS

At the initiation of this qualitative study on January 14, 2010, 27 residents from the original CASCADE study were still alive in the NH and 12 residents had died between January 15, 2009 and January 14, 2010. Among the 39 family members of these residents, one family member had died, and 13 could not be contacted for this study. Of the remaining 25 eligible family members, 16 (64%) agreed to be in the study. The majority of participants were female (63%), children of the resident (94%) and white (94%). Twelve NHs were represented, and no NH had more than 2 participants. The average age was 62 years, and the loved ones of 62% of family members were still alive at the time of interview for this study. Comparisons between participants (n=16) and those who refused participation (n=9) revealed no significant differences with respect to gender ($p=0.7$), race ($p=1.0$) or whether the resident remained alive ($p=0.7$), when tested with Fisher's exact test.

Four main themes emerged as sources of stress for family members: 1) inadequate resident personal care; 2) admission to the NH; 3) inadequate communication with health-care professionals; and 4) challenges of surrogate medical decision-making. Within these themes, certain subthemes emerged, as presented below. Themes and subthemes are listed in Table 2 and recommendations for improved care are summarized in Table 3.

Resident personal care

The quality of the residents' personal care was a major source of stress for participants, and included physical care, such as whether the resident was fed, bathed and clothed adequately, as well as emotional care and a wish for staff to treat the resident with greater respect.

ID 9-24: I thought it was custodial and adequate in terms of keeping her clean, but barely. I frequently found her with food and God knows what else caked in her fingernails which were cut very intermittently. So at the most basic level, she wasn't receiving what I think is the kind of care that any human being deserves... I felt that I never saw anybody touch her in a way that would be caring, loving, that kind of thing.

ID 21-05: They should be there to do their job with love and at least if they don't have love, at least make believe they have love.

Perceived deficiencies in physical care gave rise to two subthemes: the need to visit in order to provide direct patient care such as feeding or bathing, and the need to remain vigilant in an attempt to ensure better care.

ID 21-05: I would get to the nursing home and my mother was very thirsty and you could see that her mouth was like crusted with some kind of yellow...and everybody was going by her and not paying any attention to her. There was times that she was full of feces and her hands all over herself and screaming and no one was coming to help...Sometimes we had to give a shower to my mother because she smelled terribly, she was not being taken care of.

ID 28-15: Well, I go to feed her breakfast. I used to go and feed her supper every day, now I feed her breakfast. And also to make sure to check up on her, to make sure people are doing their jobs up there.

ID 21-05: I know the behavior was different when they realized that we were there. We would point out things that we saw.

ID 27-11: Sometimes you can get complacent with a patient like my mother. Because she just, just lies there, she doesn't require your total attention but she just lies there and she needs to be checked on.

Suggestions on how to improve resident personal care included improving perceived deficiencies in staffing, greater staff emotional involvement with care, and treating residents with respect.

ID 28-15 They don't have time for anything. They are so understaffed that they're spending all their time, you know changing people, feeding people.

ID 13-98 Treat her like she's still there. I mean don't treat her like she's like a file in the cabinet, you know, 'cause it's not like that.

Admission to the NH

Although the interview questions did not specifically address the NH admission process, some participants described stresses encountered at this time, owing to the need to make advance care plans without sufficient information about the dementia trajectory and feelings of guilt associated with the placement decision.

ID 4-155: At the time that I was asked to make those medical decisions, I didn't have a true understanding what they were and the reason for them so I didn't make them and they never came back to ask me to finish filling out the paperwork properly. I just didn't know what I wanted to do at that point and time. They were bombarding me with paperwork, like sign this and sign that and then they asked me to make end of life decisions and that is the last thing that you want to do as you put your loved one in the nursing home.

ID 13-98: My initial reaction was I felt like I was abandoning her... locking her up in a room and forgettin' about her...I think at that point, I think if there was someone around to confide in or talk, sit down and talk to about... I knew a little about the disease but I didn't know a lot and, unfortunately, I know a lot about it now.

Suggestions for how to address these concerns included greater emotional support for family members during the admission process. Recommendations for improved decision-making are discussed in relation to theme #4 below.

ID 13-98: The day that I brought her there...a little more effort could have been put into realizing the impact it had on me.

Communication with health care professionals

While the majority of participants expressed satisfaction with communication from nursing staff, there was almost unanimous dissatisfaction with the level of communication from physicians. In addition, participants expressed that due to a lack of communication regarding medical events, they were essentially unable to act as patient advocates and engage in shared decision-making.

ID 19-28: The doctor basically never spoke to me. I think I talked to him once because I insisted upon talking to him.

ID 1-36: I met the doctor once and I said to him, "I would like you to treat my mother as if she were your mother." And I have never, ever spoken to him again and that is almost 10 years.

ID 9-24: I felt like I was absolutely not made a partner in her care and my efforts to advocate for her were very unsuccessful. I gave up. I completely threw my hands up in trying to advocate for her care.

In contrast, there were several examples of satisfaction with communication with nursing staff.

ID 2-41: They'd always let me know how she's been, what's been going on with her. You know her weight, whether she ate, whether she didn't eat. You know they'd give me updates if I called in the middle of the night. And I would do that on occasion or I'd show up. You know they'd let me know what was going on.

Suggestions included improved communication from physicians, with a particular goal of engaging the family member as an equal partner in decision-making.

ID 9-24: I just never felt that I was being communicated with in the way that physicians would otherwise communicate with an intact person. So I'm an intact person, I'm representing my mother, I should've been communicated with as I would hope my personal physician would interact with me.

Surrogate medical decision-making

When asked about surrogate decision-making, many participants expressed comfort in their role. However, some felt that the responsibility was difficult to bear. Among those who felt difficulty with decision-making, two subthemes emerged: difficulty with end-of-life decisions, particularly regarding feeding tubes, and insufficient information to guide decision-making.

ID 9-24: It weighs heavily on me. It's a very hard thing for me to do and I'm hoping that I don't have to make decisions that change the course of the rest of her life. I haven't had to make any thus far but I'm preparing myself to do so when I need to.

In particular, several participants expressed stress associated with decisions regarding the use of a feeding tube.

ID 18-41: You always second guess the feeding tube. But you know, you wonder if you had a crystal ball, you know if she wasn't going to come back to be able to even talk or whatever.

ID 6-86: That was a very difficult decision to put a feeding tube in or not... she had a brain blood clot. When she came out of that, she was not eating so they put the feeding tube in and so that it became a permanent issue, as opposed to a temporary situation which we thought it was going to be and now obviously four and a half years later she is still on the feeding tube. The quality of life continues to decline pretty dramatically...Perhaps we would have made a different decision had we known the long term impact of the feeding tube has been.

The other subtheme that emerged regarding surrogate decision-making was the sense of uncertainty regarding prognosis and insufficient information to guide decision-making.

ID 21 -39: We're always asking, well what to expect and what to expect next in terms of the course of the disease but, you know, no one was quite prepared to say, this is what to expect next because I think no one really knew.

ID 9-24: ...there's been some support there but I can't say that anybody's spelled out, "Here's what's coming down the pike and here's the kinds of things you might want to consider."

Suggestions for how to improve surrogate decision-making involved greater education regarding what to expect in the course of the disease, and what treatment options are available. In addition, participants had suggestions for revisiting a discussion of advance directives after the initial NH placement.

ID 4-155: Better education of what the decisions are that you are going to be faced with and what they mean. What is a DNR, I mean what is a feeding tube? They say do you want a feeding tube? A lot of people don't know what a feeding tube is. Is it something that goes in the stomach, the trachea, I mean what is it? A lot of people don't know. A lot of people don't know what DNR is.

ID 6-86: ...they would answer the questions on a very short term basis as opposed to the long term outlook for her continued care. The ability to communicate more clearly and accurately with the longer term view would have been more appreciated.

ID 4-155: I guess they are rushed through; the feeding tube and DNR and all sorts of things. They throw that at you on the very first day and I don't know if they legally have to do it, but I just think it is just a bad time to do it.

DISCUSSION

This study utilized in-depth interviews in order to articulate themes of stress among families of NH residents with advanced dementia. Participants noted concerns relating to resident care, the NH admission process, communication with physicians, and the process of surrogate decision-making. Participants also provided recommendations for improvement in each of these domains, including improved staffing, treating residents with greater respect, and providing emotional support to families during the admission process. Recommendations to improve surrogate decision-making included greater physician communication to ensure family members are equal partners in the process, and greater education on the course of dementia and treatment options. These qualitative results add nuance to prior findings of the CASCADE study, and provide insights not obtainable through quantitative analysis alone.²²

A prominent theme among participants in this study was distress at the quality of resident personal care. Perceived inadequacies in resident personal care have been previously described in the NH setting and attributed to insufficient staffing.¹² Prior studies have also

documented that families of NH residents feel the need to remain vigilant and to become patient advocates in an attempt to improve basic care,²³ a theme endorsed by participants in our study. Family members also voiced concerns of particular concern in the case of advanced dementia, including the wish for staff to treat patients with greater respect and try to make an emotional connection despite the limitations imposed by the disease. Additionally, they noted that residents with end-stage dementia were particularly prone to neglect due to their inability to interact with staff or advocate for themselves. Our finding that family members expressed a belief that visitation and vigilance were needed in order to ensure adequate resident care may shed light on prior findings from the CASCADE study which indicate that lack of family member visitation was associated with lower quality care.²⁴ This work also found that very high levels of visitation were associated with lower quality care, which may reflect the family members' perceived need for greater oversight.

The NH admission process was noted by participants in our study to be difficult, in part due to the feelings of guilt associated with institutionalization. Such guilt is likely due to the fact that the majority of patients with dementia are cared for in the community by family members prior to NH placement, and the decision to institutionalize may be viewed as a failure or breach of trust.²⁵ The provision of emotional support to families at this pivotal transition to address feelings of guilt and to aid with adjustment to the NH environment may be particularly useful, and have ramifications for the duration of NH stay and perhaps beyond. Participants also noted that they did not feel that the NH admission was the optimal time to discuss advance care planning, due to the overwhelming context of emotional stress. This stance is supported by expert opinion that advance care planning should involve conversations that take place over time, guided by changes in patient status.²⁶ Further, recognizing the difficulties inherent in planning for future medical events, the focus of advance care planning has recently evolved from a static mechanism to document predefined care preferences, toward a more fluid process of education and guidance in order to prepare patients and surrogates to make the best possible in-the-moment decisions as they arise.²⁷ Our findings support a prior report from the CASCADE study indicating that greater time spent discussing advance care planning is associated with greater family member satisfaction.¹⁸

Our results documenting family members' perception of poor communication with NH physicians is supported by prior literature,²⁸ particularly in the case of end-of-life care where it has translated into distress at a lack of information regarding the dying process.¹² Such lack of information may be particularly problematic in the case of advanced dementia, since residents are unable to communicate with family members, and because information regarding the end-of-life process is of particular importance due to the difficulties in prognostication.

Surrogate decision-making for patients with advanced dementia is challenging for many reasons. Patients often have a prolonged period of cognitive impairment during which they have been unable to voice preferences for treatment. Thus, surrogate decision makers may be asked to play a greater role than in other end-of-life conditions. Prior studies of family members of NH residents with dementia document that while the majority endorse comfort as the goal of care,²⁹ families have great difficulty in translating this broad goal into specific treatment choices.²⁵ In fact, NH residents with advanced dementia often receive care that is not consistent with palliation.^{6,29} Additionally, as participants in our study noted, a lack of understanding of the disease trajectory impairs decision-making, and impedes the ability to incorporate broad goals of care into treatment plans.²⁵ Participants in our study reported a need for greater education from physicians and other NH staff regarding dementia and what to expect as the disease progresses.

Our results should be interpreted in light of certain limitations. Our study was relatively small, although our sample size was adequate for qualitative analysis.³⁰ Our study design relied on subject recall, particularly for family members of residents who had died, which may pose potential limitations to the validity of our results. However, we limited the length of time between resident death and subject interviews in order to minimize this concern. Participants in our sample, and the NHs where care was delivered, were located in the Boston area, and the majority of family members were female, white and children of the residents, which may limit the generalizability of our findings.

Although NHs provide the majority of end-of-life care to patients with advanced dementia, our results echo prior research documenting perceived deficiencies in NH care, and highlight specific family member concerns related to advanced dementia. Optimal end-of-life care includes the provision of physical comfort and emotional support to patients, care focused on patient dignity, attention to the emotional needs of family members, and promotion of a shared decision-making process.⁸ Family members in our study noted concerns and recommendations for improvements in each of these domains, within the specific context of advanced dementia and the NH setting. In particular, recommendations included greater education regarding the course of dementia and support during the process of surrogate decision-making, including advance care planning. The implementation of recommendations outlined by subjects in our study may help to address the concerns of the millions of family members who rely on NHs to care for their loved ones with advanced dementia.

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Table One

Sample Interview Questions

Domain	Sample questions
Overall perceptions	How would you describe the overall experience of having your [mother/father etc] cared for in the nursing home for dementia?
Communication	How would you describe the communication you had with your [mother/father's etc] doctors and nurses? What could have gone better with how the doctors and nurses communicated with you?
Surrogate decision-making	How do you feel about the level of involvement you had in making medical decisions? Did you ever have a hard time understanding the medical decisions you were asked to make?
Emotional distress Recommendations	Was it difficult to let others take care of your [mother/father etc]? Do you have any recommendations about how staff in the nursing home can provide more support to you as a family member of a loved one with dementia?

Table Two

Themes and Subthemes

Theme	Subtheme	
Inadequate resident personal care	1	Need to visit in order to perform direct care
	2	Need to remain vigilant
Stress at time of resident admission to the nursing home	1	Emotional strain and guilt
	2	Timing of advance care planning
Communication with health care professionals	1	Lack of physician communication
	2	Being left out of medical decisions
Surrogate decision-making	1	Difficult end-of-life decisions such as the use of feeding tubes
	2	Insufficient information to guide surrogate decision-making

Table Three

Recommendations for improvement in nursing home care organized by themes	
Resident personal care	
1	Improved staffing
2	Greater staff emotional involvement when providing care
3	Treating residents with respect
Resident admission to the nursing home	
1	Emotional support for families during admission process
2	Separation of advance care planning from the immediate admission process
Communication with health care professionals	
1	Greater communication, specifically with physicians, with the goal of engaging family members as equals in decision-making process
Surrogate decision-making	
1	Greater education for family members on the course of dementia
2	Greater explanation of treatment options
3	Greater information and education on common decisions (e.g. treatment of feeding problems)