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What is Family-Centered Care for Nursing Home Residents With Advanced Dementia?

Ruth Palan Lopez, PhD, GNP-BC¹, Kathleen M. Mazor, EdD², Susan L. Mitchell, MD, MPH^{3,4}, and Jane L. Givens, MD, MSCE^{3,4}

¹MGH Institute of Health Professions, School of Nursing, Boston, MA, USA

²Meyers Primary Care Institute, University of Massachusetts Medical School, Worcester, MA, USA

³Hebrew SeniorLife, Institute for Aging Research, Boston, MA, USA

⁴Division of Gerontology, Beth Israel Deaconess Medical Center, Boston, MA, USA

Abstract

To understand family members' perspectives on person- and family-centered end-of-life care provided to nursing home (NH) residents with advanced dementia, we conducted a qualitative follow-up interview with 16 respondents who had participated in an earlier prospective study, Choices, Attitudes, and Strategies for Care of Advance Dementia at End of Life (CASCADE). Family members of NH residents (N = 16) with advanced dementia participated in semistructured qualitative interviews that inquired about overall NH experience, communication, surrogate decision making, emotional reaction, and recommendations for improvement. Analysis identified 5 areas considered important by family members: (1) providing basic care; (2) ensuring safety and security; (3) creating a sense of belonging and attachment; (4) fostering self-esteem and self-efficacy; and (5) coming to terms with the experience. These themes can provide a framework for creating and testing strategies to meet the goal of person- and family-centered care.

Keywords

qualitative research; nursing homes; dementia; terminal care; person-centered care

Introduction

Alzheimer's disease, the sixth-leading cause of death in the United States, affects 5.4 million Americans¹ and is an independent predictor of first time and long-term nursing home (NH) use and death.² Data suggest that end-of-life care provided in NHs is inadequate. Family members report dissatisfaction with poor-quality care that is task focused rather than person

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Corresponding Author: Ruth Palan Lopez, PhD, GNP-BC, MGH Institute of Health Professions, School of Nursing, 36 First Avenue, Charlestown Navy Yard, Boston, MA 02129, USA. rlopez@mghihp.edu.

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centered.³⁻⁵ The NH residents who die from dementia often have unmet needs, experience burdensome interventions such as hospitalization and feeding tubes, and distressing symptoms.⁶⁻⁸ Efforts to improve care have focused on shifting the paradigm of care from task focused to person and family focused. Despite considerable influence on policy and practice, the concepts of person- and family-focused care are not well defined.

The concept of person-centered care for persons with dementia was discussed in the literature by Kitwood⁹ who suggests that people with dementia do not progressively “lose” themselves but instead, maintain their personhood through relationships and social interactions and by Algase and colleagues¹⁰ who furthered the concept of person-centered care by reframing problem behaviors from a symptom of dementia to an expression of unmet needs. Edvardsson and colleagues examined the literature and identified the following components of person-centered care: acknowledging the personhood of an individual with dementia is increasingly hidden or changed but not lost; striving to honor the personhood of people with dementia in all aspects of care; personalizing care and surroundings; offering shared decision making; interpreting behavior from the person’s viewpoint; and prioritizing relationships to the same extent as care tasks.¹¹ Their qualitative study of NH staff, family members, and people with early dementia extended the concept to include promoting continuity of self and normality through knowing the person, welcoming the family, providing meaningful activities, personalized environment, and expressing flexibility. The concept of person-centered care was expanded to include “family-centered care,” which acknowledges the important role of the family or other loved ones in the patient’s final days.¹²

Although there is consensus that high-quality care is person and family focused, strategies to operationalize these principles are lacking. Therefore, the purpose of this study was to examine data from family members of NH residents with advanced dementia through semistructured, open-ended interviews to identify attributes of person- and family-centered care for NH residents with advanced dementia. A better understanding of these attributes may lead to improved care by identifying quality indicators and effective strategies to provide person- and family-centered care to this population.

Methods

Design

We used a qualitative descriptive design to identify attributes of person- and family-centered care.¹³ This is the qualitative method of choice to provide an in-depth description of the phenomenon in the words of those involved. We utilized data generated from semistructured, open-ended interviews via telephone with 16 family members. These data were previously analyzed using constant comparative method to identify sources of stress for family members and published elsewhere.¹⁴ For this study, we analyzed the data using thematic analysis to identify attributes of person- and family-centered care.¹⁵

Participants

The population was drawn from a previously conducted prospective study of NH residents with advanced dementia, Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End of Life (CASCADE).¹⁶ Patients in the CASCADE study consisted of dyads of NH residents with advanced dementia and their family member. The parent study was conducted between February 2003 and 2009. Eligibility criteria for residents included age > 65 years, a cognitive performance score¹⁷ of 5 or 6 on their most recent minimum data set cognitive impairment due to dementia, global deterioration scale¹⁸ score of 7, length of stay 30 days, and the availability of a family member who was willing to participate and could communicate in English. The CASCADE study was conducted in 22 NHs.

Eligibility criteria to participate in this follow-up study included (1) family member of the resident; (2) resident was either alive in the NH on January 14, 2010, or died in the prior year; and (3) family member completed the CASCADE study and was able to be contacted. Family members of the residents who died more than 1 year prior to the study were excluded due to concerns regarding adequate recall of events. In all, 25 family members were eligible to participate, and 16 (64%) agreed to be in the study. The project was approved by the institutional review board of Hebrew SeniorLife, and written consent was obtained from each participant.

Data Collection

We collected data using a semistructured, open-ended interview protocol. We did not direct participants to the concepts of person- or family-centered care. Instead, we asked participants to discuss their experience with NH care at end of life for residents with advanced dementia. Two professional research assistants trained in qualitative interview methods asked about overall NH experience, communication, surrogate decision making, emotional reaction, and recommendations for improvement. Interviews lasted for 19 to 123 minutes (average 50 minutes).

Data Analysis

Interviews were audiorecorded, professionally transcribed, and entered into NVivo software (QSR International Pty Ltd 2003, Victoria, Australia). Two members of the research team (JLG and RPL) analyzed the data using inductive theoretical analysis.¹⁵ First, we read each transcript individually to familiarize ourselves with the data and noted initial ideas. Second, we generated codes across the data set and collated data relevant to each code. Third, we collated codes into themes. Finally, we examined the themes at the level of the coded data extracts and the entire data set to ensure that the themes accurately and adequately reflected both the individual codes and the perspectives expressed in the entire data set. Final results were reviewed by the entire research team to determine that findings were plausible and valid.

Results

Participants

The majority (63%) of the participants were female, children of the resident (94%), and white (94%). In all, 12 NHs were represented, and no NH had more than 2 patients. The average age of participants was 62 years, and of those interviewed, 62% had residents who were alive at the time of interview for this study.

Themes

Analysis of the data identified 5 themes related to person- and family-centered end-of-life care: (1) providing basic care; (2) ensuring safety and security; (3) creating a sense of belonging and attachment; (4) fostering self-esteem and self-efficacy; and (5) coming to terms with the experience.

Providing Basic Care

All the participants expressed the importance of basic care including, food, cleanliness, and comfort. Basic care was an essential ingredient in family members' definition of "being cared for." Family members said:

There were good times, at times we went there and she was dressed nicely and so we felt good that she was well taken care of.

I didn't have to worry that she wasn't being cleaned. And she was always well taken care of. She didn't have any odors to her. She didn't have any markings on her. She was always well taken care of.

They feed her. They dress her. They clean her, what can they do? They can't make her young. They can't make her well. They take care of her, that is what they do.

Alternately, descriptions of bad care included lack of basic care. A husband expressed his dissatisfaction with the care his wife received reporting, "All the times that we were dissatisfied is when she [resident] has her hair done and they comb it out." Another family member complained that they often "found her [resident] dirty with food all over her shoes."

Ensuring Safety and Security

Family members wanted to be assured that their residents were safe and secure. This was achieved when NH staff identified changes in residents' conditions and notified family members promptly. In the words of 1 family member "She was being taken care of around-the-clock, twenty-fours a day, something I couldn't give her personally." They wanted to be notified of changes in residents' condition in a timely manner, regardless of how insignificant the problem may be. A daughter said, "If my mother has had an issue, a bruise or scratched herself and caused herself to bleed or whatever, the nurse is usually right on top of it, and if I am not there, since I am there very often, I get a phone call from the nurse letting me know what happened to my mom. That is really good." Another family member reported, "If in fact something did happen they called me immediately and told me what the problem was. So I felt good about having her there. I knew she was safe." When family members' did not feel a sense of safety and security they described their needed to remain

vigilant, “something that was always in the back of your mind.” Feeling insecure was “not really like, ‘okay, she’s great. She is well taken care of. We don’t have to worry.’ No. It was not like that. We just had to be constantly there checking things out.” Feeling insecure was described as “something that was always in the back of your mind.”

Creating a Sense of Belonging and Attachment

Participants voiced the importance of creating a sense of belonging and attachment. This included the relationship both between residents and staff and between family members and staff. Participants experienced a sense of belonging and attachment when care was “personalized” and staff “knew her [resident] quite well.” It also included the relationship between staff and family members. For example, some family members spoke about making a point of getting to know the staff and expressing their appreciation to staff. A daughter said:

It would be nice if I knew who her aide was so I could make the aide feel important and give some more positive feedback to the aide to make them feel good. To say, ‘Oh gee, you really did a nice job dressing my mother today, she looks so nice. You really picked out a nice outfit for her.’ Cause I know they have really tough jobs, and how else can I show my appreciation to them unless I know who her aide is on any given day.

Another daughter said, “I brought up chocolates and stuff for the staff ... because I felt that they went above and beyond ... caring for her as if she was their own.” Family members also appreciated receiving emotional support from staff. One daughter described difficulty coping with her mother’s declining cognition. She said:

It was hard for me to grasp the fact that it was happening, but it ultimately resulted in her being moved off of her original floor where she had probably been for four years or five years or so and being moved to another floor. I will say that the staff of the floor where she went to was as concerned with my adjustment to the situation as they were with hers. I think that was at the time, reflecting on it now, that was wise because I think it may have been as hard for me as it was for her.

In contrast, when family members did not experience a sense of belonging they felt detached and isolated. A daughter dramatically described her sense of isolation in dealing with her mother’s dementia:

It has become very isolating for me in that my siblings they have no responsibility for you know, supporting me because one of them lives far away and one of them has mental health problems. So it’s been a very challenging, very isolating experience and I did approach the social work department at the facility asking if they might hook up people like me who had a parent with dementia for these kinds of periods of time. So I would’ve hoped that the facility might take a look at what it takes to support a family dealing with this and there was no concept of it being an issue for the family. It was entirely focused on the individual and they would’ve had a much happier camper in me had they possible put together some kind of group, put people in touch with one another to give that kind of support. So it’s

been a very trying and overall sad experience and lonely experience of dealing with this kind of protracted dementia.

Fostering Self-Esteem and Self-Efficacy

Participants also spoke about the significance of achieving a sense of self-esteem and self-efficacy when they were successful in advocating for and making surrogate decisions for residents. They described pride in their ability to remain actively involved in and advocating for residents' needs, knowing residents' preferences for end-of-life care, and making end-of-life decisions consistent with these preferences. A family member was proud of her ability to be "there often enough to see what is going on and [stay] on top of the nurses or my mother's aide for the day. They don't have to make as many phone calls to me as maybe they make to other caregivers who don't go as often." Another reported, "I am not your typical Alzheimer's caregiver in that I am a very well educated caregiver." In contrast, a few family members were frustrated in their roles as decision makers. A daughter said, "Now that feeding tube it turned out that they couldn't take it out because she basically lost her ability to eat and the ramifications of that although complex, were not clearly explained to us in a way that ... we probably made the decision too quickly." Another family member was frustrated in her role as decision maker. She said, "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."

Coming to Terms

Several participants mentioned the importance of accepting the final stage of life and coming to terms with the NH experience. They reflected on their decisions to place their loved one in the NH and to come to terms with how life was ending as the following quotations illustrate:

It's made my life totally easier. I couldn't take care of her. She requires twenty-four hour care. I have two children and a husband and work, and I couldn't do it. And I feel guilty for that but that's that.

No, it certainly made it easier for me to do and meet up to my responsibilities as far as raising my family. My husband never gave me a problem about the inordinately large amount of time that was necessary before my mother went there. The responsibility that I had for taking care of her, but it really did enable me to interact with my family more normally.

Again, I think it freed me up to do all those things. I just felt indebted, my life in general, was improved by the fact that she was there. I will say that I think that most of the time I had a reasonably realistic point of view, where I didn't beat myself up too much for the fact that she was there because I was aware that there were really not anyway that she could have been with me in my home. It would not have been safe for her and it would really not have been conducive to good family life in my home.

However, some family members continued to lament their NH placement decision. They said:

You know my mother worked her whole life. When I was a kid she was one of the few mothers that worked full time taking a train into Boston every day from the suburbs, and mothers didn't do that. She worked hard all of her life for that money and it's just, every month writing a check for seven or eight thousand dollars. She would have died if she realized it.

I had feelings at that point of what a drag this is, you know? And then of course, I had a guilt trip about that. Because then I would remind myself that she probably felt the same way when I was an infant.

Discussion

Although person- and family-centered care is advocated as a means of improving the quality of care in NHs, we understand little about what constitutes this type of care for residents with advanced dementia and their family members. Our analysis of data collected through semistructured, open-ended interview found 5 themes, the provision of basic care, ensuring safety and security, creating a sense of belonging and attachment, fostering self-esteem, and coming to terms with the experience. This study offers a unique perspective on family members' experience of NH care and contributes to our current understanding of person-and family-centered care.

Our findings lend additional support to calls for the provision of adequate basic resident care and prior research demonstrating that failure to address the needs of dying residents increases burden for both patients and family members.^{3,5} Previous research demonstrated that greater decision-making satisfaction is associated with greater resident comfort,^{19,20} suggesting that addressing residents' needs for basic care influences family members' perceptions of decision making. Research is needed to examine the relationship between these elements and to explore whether perhaps they represent a hierarchy of needs such that meeting basic needs enables family members to engage in more complex concerns such as surrogate decision making.

We also found that frequent, timely communication with family members created a sense of safety and security. Communication is an important factor in predicting family member satisfaction with end-of-life care.²⁰ Research is needed to determine whether interventions that enhance family members' sense of safety and security with NH care reduces family members' vigilance, stress associated with NH placement, and preferences for hospital transfers.^{5,21}

The third theme, belonging and attachment, suggests that rather than individual choice and autonomy, endorsed by much of the person-centered literature,^{22,23} participants in this study valued connections with NH staff and other family members. Fostering a community of support between family and staff may not only support family members, but research suggests that interventions that involve family members in NH care improves both the care-giving experience for family members and the staff attitudes toward family members.²⁴

The fourth theme, self-esteem and self-efficacy, suggests a relationship between surrogate decision making and feelings of confidence. Surrogate decision making for patients with

advanced dementia is common for family members,²⁵ although prior research suggests that they feel unprepared and unsupported in making medical decisions in the NH setting.^{26–29} Surrogate decision making can be stressful, however, supporting self-efficacy for decision making may reduce uncertainty and possibly produce better outcomes for surrogates.³⁰

Finally, several participants in this study reported coming to terms with the final stage of life and the NH experience. This element may be similar to an important element of a “good death” identified by Steinhauer et al, sense of completion, whereby participants in her study placed deep importance on meaningfulness at the end of life.³¹ Perhaps family members also need time to perform a life review, resolve conflicts, and say good-bye. Consequently, this finding may hold implications for family members’ ability to make palliative care decisions.

This study also offers a unique perspective on person- and family-centered care, because rather than simply providing a list of areas of improvement, these findings put forward the possibility that family members’ priorities could be structured in a hierarchy, much like Maslow’s Hierarchy of Needs.³² If these 5 attributes of person- and family-centered care were structured in a hierarchy, it would suggest that lower needs, basic care, safety, and belonging must be met before family members are able to move to higher level needs such as achieving self-esteem and coming to terms with the experience. This holds important implications for end-of-life decisions that family members often make. Additional research is needed to determine whether satisfying these fundamental elements not only improves satisfaction with end-of-life care but also improves satisfaction with decision making,¹⁹ self-efficacy for surrogate decision making,³³ and diminishes the use of burdensome interventions such as feeding tubes and unnecessary hospitalization.

Our study has several limitations. The sample was homogeneous, and our findings do not reflect changes in perceptions over time. In addition, it is possible that not all themes were expressed. Although the findings may not be widely generalizable, they do generate important hypotheses to be tested in subsequent studies. The findings may also be transferable to assisted living facilities (ALFs) that are similar to NHs in process and outcome,³⁴ and research indicates that the quality and nature of resident, ALF staff, and hospice relationships are critical to promoting quality end-of-life care.³⁵ Finally, bereaved family members of persons dying from dementia who received hospice reported fewer unmet needs and concerns with quality of care.³⁶ Additional research is needed to determine whether satisfaction associated with hospice is associated with family members’ perceptions of person- and family-centered care.

In conclusion, we identified essential components of person and family-centered care. These elements can serve as a framework for addressing areas important to family members. Additional research is needed to explore relationships between meeting these needs and family members’ achieving a sense of confidence in their surrogate decision making and their ability to come to terms with the experience.

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