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Preserving Personhood of Individuals with Advanced Dementia: Lessons from Family Caregivers

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Abstract

This article reports on a phenomenological study of 15 family caregivers who admitted their spouse or parent with probable Alzheimer's disease to long-term care. The caregivers were attuned to the needs, desires, moods and concerns of their family members with dementia; thus, they were attuned to personhood. Caregivers also reported observations of care by nurses and nursing staff. Observations were of individualized care and actions that promoted personhood and impoverished care delivered with minimal or no communication. These family caregivers' perspectives can inform the care of individuals with advanced dementia by nurses and nursing staff.

Keywords

personhood; dementia; Alzheimer's disease; caregiver; long-term care

“...And I'm like at what point do we [start] treating them like they aren't even here?” (Adult Daughter)

Alzheimer's disease, which affects 5.4 million Americans, is the most common type of dementia¹. While an estimated 70% of persons with Alzheimer's disease reside in their homes, the progression of cognitive decline increases the prospect of admission to a long-term care facility^{2, 3}. It is estimated that half or more of all persons with dementia in the U.S. will be admitted to long-term care during the course of their illness and approximately 68% of all long-term care residents have some cognitive impairment^{1, 4, 5}

Kitwood⁶ has defined personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust” (p. 8). Acknowledging personhood involves recognizing the needs, wants, emotions, personality, relationships (or need for relationships) and life story of the individual. Peoples' perception of the personhood of someone with diminished cognitive abilities may change with a diagnosis of dementia. Discounting the individual's concerns,

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moods, behaviors, and background often coincide with diminishing cognitive abilities until recognition of the individual as a perceiving and responding being is lost.

Alzheimer's disease gradually robs the individual of memory and skillful ways of being in the world. Phinney⁷ found that individuals with dementia experienced "being slow", "being lost", and "being blank" as they tried to navigate their environment. Phinney also reported that familiar routines and structured activities provided by family caregivers enhanced coping with change and helped the individuals with dementia navigate their environment⁷. Similarly, Perry and O'Connor⁸ found that caregivers' activities to preserve the personhood of their spouse with dementia included "maintaining continuity" to the life of the person with dementia by telling stories of the past and interpreting behaviors and needs based on their shared past; "supporting competencies" in daily activities; "protecting from incompetence" and the appearance of incompetence of the person with dementia; and by "strategizing encounters" of the person with dementia with others so as to project an appearance of normalcy, to allow the person with dementia to appear at his or her best, and/or to foster acceptance by others⁸.

Family members also bring knowledge of ways to preserve personhood when a person with dementia is admitted to long-term care. New residents face an unfamiliar institutional environment and disrupted routines. Family caregivers can serve as the link between the resident with dementia and the long-term care staff. Photos, personalized items, stories, and observations from family members can foster understanding of the resident's past, relationships, needs, and preferences. One study of family caregivers' experiences following long-term care placement found that caregivers desired to be asked for their knowledge about the needs, behaviors, and routines of their family members and to be listened to when they offered advice⁹.

Cognitive impairment can affect how individuals are perceived and responded to by others^{6, 10}. This is especially true when individuals who have advanced dementia are being cared for by nursing staff who may not know the individual's history: Persons with dementia face the risk that their personhood will be discounted. This article reports family caregivers' efforts to preserve the personhood of individuals with advanced dementia when they were moved to a long-term care facility. Although the reported study is of family caregivers in the long-term care setting, their experiences inform the care by nurses of individuals with dementia regardless of setting.

The family caregivers struggled to preserve recognition of their family members with dementia as perceiving, responding and relating persons, instead of objects to be positioned and cleaned. They observed behaviors by nurses and nursing staff that helped to maintain the personhood of their loved ones, and also behaviors that discounted them.

METHOD

Hermeneutic phenomenology was the method of inquiry in this qualitative study¹¹. This method provides an opportunity to explore the complex, meaning-filled experiences of

relationships between caregivers and their family member with dementia in a long-term care facility.

Subject Selection and Sample

A convenience sample of 15 participants was recruited following presentations to support groups, distribution of flyers to clinicians and nursing home staff, and advertisements in nursing home newsletters, targeted newspapers and church bulletins. To be eligible for the study, participants had to have placed their family member with Alzheimer's disease in a long-term care setting within the previous 12 months, speak English, and be able to physically and cognitively complete screening questionnaires. The age range of 40 to 100 years old was used as an inclusion criterion because of concern that individuals outside this age range would be in unique caregiving situations that were less generalizable to the larger population of caregivers. Institutional Review Board approval was obtained prior to study initiation. Participants were recruited until no new themes emerged from the narratives. Table 1 summarizes participants' characteristics.

Participants' experiences were in rural and urban, private-for-profit facilities, Veterans' Administration nursing homes, mixed Medicare and Medicaid, and some almost entirely Medicaid supported facilities. Two participants had spouses in the same facility: the other 13 caregivers' experiences were in 13 different long-term care facilities.

Data Collection

All participants completed three 90 to 135 minute interviews except for one daughter who completed only the first and last interview sessions because of her mother's death. The sessions were scheduled 30 days [± 10 days] apart and took place in the caregivers' homes, except for one daughter who chose to do her interviews in a private space at the long-term care facility.

Data Analysis

All interviews were conducted by the researcher and were based on the author's prior work with family caregivers and individuals with dementia and in long-term care. A series of open-ended questions were developed to guide the interview sessions¹². Table 2 gives a sample of these questions. The interviews were digitally recorded and prepared for coding by a professional transcriptionist. Participants were assigned a pseudonym and code number. Also, participant identifiers and contact information were stored separately from research documents.

The author read, coded, re-read, and re-coded the typed narratives, searching for patterns, gaps, contradictions and meanings hidden in the caregivers' everyday practices. Transcripts were considered by themselves and along with the transcripts of other participants to explore the experiences and patterns of involvement of family caregivers who admitted their family members with dementia into long-term care.

Throughout the process the author maintained an audit trail of decisions¹³. An interpretive group met on three occasions to review with the author those transcripts that were

particularly salient or puzzling and to confirm and challenge interpretations¹⁴. The 4 to 7 member interpretive group always included a nurse researcher with expertise in qualitative research, specifically interpretive phenomenology. Other members included nurse researchers with recent research and publication in interpretive phenomenology and nursing doctoral students conducting interpretive dissertation studies. In addition, the author consulted with experts in interpretive phenomenology and geriatric nursing care during the analysis.

RESULTS

Caregiver participants in this study were involved in the nursing home care of their family members with dementia. Caregivers maintained their family members' personhood through their involvement with care. They recognized and responded to the personhood of their family members with dementia and they observed practices that supported the personhood of individuals with dementia and practices that discounted personhood. Caregivers' experiences related to the personhood of the person with dementia are described below.

Practices that Discounted Personhood

The forgetfulness, changes in judgment and orientation, and other cognitive losses, that occur with Alzheimer's disease and most other dementias increase the person's vulnerability to being discounted. One daughter within the study noted, "It's a devilish disease. It's so unlike cancer or leukemia or Parkinson's disease or any of these diseases that you can name. It's so different because it robs the essence of a person." Family members watched as the person with dementia became increasingly dependent and "blank". Another daughter said:

Yesterday she just had the smile that I'm used to. She had her in her eyes and she was smiling. It made me feel really good to see that, because I haven't seen that in a long, long time. [Often I see] just a blank stare. Staring out into where? I don't know but yesterday she was with us and that made my day.

Disease progression also reduces ability to perform self-care. Assisting residents to complete daily activities of dressing, bathing, eating, and toileting can become time-consuming. The person with advanced dementia becomes vulnerable to practices that are rushed and that show decreased respect for their slowed body. One daughter described her experience with an aide who wanted to change her mother's care in a way that would further take away her identity:

They wanted to stop dressing her in street clothes and just put her in a hospital gown, but I'm sure...that the biggest thing is she [the aide] doesn't want to work that hard. She doesn't want to be gentle with mom. She doesn't want to have to take the time and the care that it takes to dress her [Mom] without hurting her. She [the aide] wants to just throw something on her [Mom] and be done...and I said "I don't want it". "I do not want it". If she [Mom] was bedridden we'll talk, but she's not. If she was out in the hallway in a gown or even a duster or a robe, she would be mortified.

The person with advanced dementia thus becomes vulnerable to practices that disregard their existence as a living being. Some family caregivers observed disregard for the basic needs of eating and toileting with their family member. One spouse said:

I found him in bed with a cold tray of food on his bedside table and this was like at 6:00 [in the evening] and the door [was] shut...Obviously nobody was going to feed him. So I went down to the nurse and said "Is anybody going to feed him?" And some aide came up and said, "I've already fed him." I went down to the room...and I picked up the tray...

This man would not have been fed his dinner if his wife had not come to check on him. The wife was leaving town and she was worried that her husband's basic needs, including being fed, would not be met in her absence.

She was not alone in her worries. Although family caregivers did not know what happened in the long-term care setting in their absence, they usually believed (or wanted to believe) that the basic needs of residents were addressed. However, there were times when family caregivers recognized that their loved one was cold, hungry, and needed to toilet and long-term care staff were not identifying the needs and doing something about them or-- they, chose not to. This was a worry to family caregivers. One said,

I'd come out there in the mornings and she's sitting in a t-shirt and it's cold. That aggravates me. I feel her skin and she's just cold. She's not complaining and she can't tell them. I have to go and get a sweater...

In addition to concerns about basic needs being met, some family caregivers witnessed care practices that negated personhood and disrespected the dignity of the person with dementia. One daughter shared this experience:

They had a habit for a while of taking off her diaper and pulling down her pants and leaving them around her ankles [at nap time] and it bothered me. One time when I happened to be there when she was waking up from her nap, she was just squirming and moving all over that bed and frowning. I kept saying, "Mom, what's wrong?" "Nothing". "Does something hurt?" "No."...I finally figured out that she's trying to move her legs and can't. Who of us would lay down for a nap and pull our pants down around our ankles and leave them there? None of us.

When her mother's pants were not completely removed, the pants acted as a leg restraint that limited movement. This practice was unsafe, dehumanizing and disrespectful of the resident's dignity.

Most of the family caregivers interviewed had been responsible for their loved one's care 24 hours a day/ 7 days a week prior to admission. The caregivers thought about their family members with dementia even when they were not with them. Many wondered if needs were being met when they were not at the facility. One daughter told how her father came to every mealtime session at the long-term care facility so that he could feed his wife. The daughter said her father did this because once they observed a resident in the dining room who did not get fed until her father said something as the resident was being wheeled away.

These family caregivers feared that at some point in the progression of the disease, the staff would no longer notice or try at all to relate to the individual with dementia as a person. They worried that a social death would precede the physical death. Benner and Wrubel¹⁵ have said that social death occurs when individuals “cease to notice that the person is still alive, still has a world, still has concerns” (p. 16). Fearing the early social death of her husband in the eyes of friends and support group members, one caregiver said she told them, “Life doesn’t come to an end when they’re placed...”.

Practices that Supported Personhood

Knowing the personhood of another considers the attributes that define the person, including history, roles, beliefs, and values. These family caregivers’ stories were filled with examples of knowing and responding to the personhood of residents with dementia. Knowing the person’s past, many family caregivers brought favorite foods and personal items from home. Some caregivers planned or participated in activities they knew their family members enjoyed. One wife said:

They have music Monday, Wednesday and Friday, and sometimes I can get him and we dance after we eat lunch. We usually dance a good half hour and that really makes the other people feel good...it just makes the whole place feel better...He loves dancing.

An individuals’ ability to relate to others and to form relationships is an aspect of their personhood. Caregivers’ narratives included examples of staff relating to individuals with dementia by acknowledging their history, likes, and dislikes. One daughter noted:

I’ve come across some really good people there, and Louise especially, she will talk to my mom and use her name and she already says, “Your mom likes vanilla”. She already knows things about mom that make me feel she’s paying attention to this person as an individual. I like that. I like to think that they’re seeing a little bit of a personality too, not just a person that needs to be taken care of.

As study participants observed interactions between staff and residents, they looked for care and conversation that conveyed compassion and value. One daughter explained:

I can tell you right now who I feel more relaxed when I know they’re on duty than those people that I don’t. There’s one nurse there...and honestly I don’t think that I’ve ever seen her interact with any of the residents and that scares me. There’s a med tech...I don’t know that I’ve ever even seen her smile. She comes in, gives them their meds and that’s about it. They give some of them meds like in I guess pudding or something and it’s....well I wouldn’t want it shoved into my mouth like that. I mean can you even say, “Hi, how are you feeling?” When Rita is on duty, she likes those residents. When Kris is there, I know she keeps an eye on Mom. She comes in and makes sure that mom goes to the bathroom and doesn’t sit....To me, it isn’t just about giving them meds. It is about how they are making them feel that they’re still valuable and they’re still loved, and somebody really cares.

One wife explained how simple interactions could make a difference to her husband:

It means a lot to me when they go the extra mile to do extra things for them. Sometimes you don't even have to do a lot, sometimes when you just reach and grab his hand and say, "Mr. J. it's going to be okay". The tone of your voice [is important] because he doesn't respond to a lot of sternness. You can just hold his hand, and then sometimes he'll light up like a Christmas tree...It doesn't cost anybody to say "Hello", "How are you doing?", "Hang in there!", "Love you", pat you on the back, [and say] "You're going to be okay"....

Another spouse believed that having consistent staff was important for knowing the needs of her husband with dementia:

Bless their hearts, they are getting a little more stable [at consistent staffing]. They do change, too much unfortunately. So, there isn't consistent care [and knowing] what works best for him....They move them from hallway to hallway too, which if they'd leave them on one hall...

Elopement risk prevented one man with dementia from admission to a modern nursing home that was close to home. His wife was disappointed when he ended up in an older place, but she soon discovered that the looks of the facility were not as important as being treated like family:

You cannot walk by a staff member from the bottom all the way to the top, to the owner without them speaking to you and knowing your name. Every single one of them. The laundry girls in there know him and say, "Hi George"...This place is old, the floors are kind of wavy, the closet doors are metal and it's very difficult to close them. You never have an odor like in some nursing homes and the people, they treat everybody like family. These are happy days for him and for me too. As I'm going down the hall, I've got people waving at me from all over. A few patients and a few staff members...They are happy to see me and they are happy to see him when he walks down the hall. He likes all of them and they all like him.

Another wife explained how the initial welcome of her husband to the long-term care facility made him more comfortable.

The camaraderie out there is great. The day he was admitted there must have been at least 20 people there to greet us...and everyone knew his name. I said, "You must have sent out a bulletin or something with his picture on it" because everyone knew who he was.

Also, the family caregivers gave examples of individualized care that recognized the needs of individuals with dementia and demonstrated respect for personhood. For example, one wife shared this about her husband:

Sometimes Mr. Dewey is a handful. I know that he's a handful...Yesterday he was a little agitated so they gave him his medicine and put him to bed. Mr. Dewey had been up since 3, 4, 5:00 that morning walking. The aide said Mr. Dewey had a good day and that he had been walking all day. So the aide had put him to bed...

The staff recognized that Mr. Dewey was tired from getting up early and walking all day. When Mr. Dewey started getting agitated, the staff helped him to bed.

In summary, these family caregivers' everyday experiences in the long-term care setting reflected practices that discounted and practices that recognized and supported the personhood of residents with dementia. As the persons with dementia became increasingly silent, caregivers worried that a long period of social death would precede the physical death of their loved one. The ultimate disregard for personhood, social death, was a concern for many caregivers and it increased their stress and concern about the placement situation.

DISCUSSION

A primary finding of this study was that the interviewed family caregivers provided person-centered care that acknowledged the personhood of the individuals with dementia. For example, they conversed with their family members in the way they hoped the staff would. Meeting the basic care needs of the person with dementia was their priority: they anticipated these needs. They believed, without exception, that the feeding, toileting, bathing, comfort and security needs of the person with dementia must be met. Furthermore, the caregivers took the person with dementia to activities consistent with the person's interests. They helped the person with dementia to maintain their appearance believing this made the person feel better about themselves or at least, prompted respectful treatment by others. Application of the caregivers' knowledge of the care of the person with dementia can help to guide the practice of nurses in the promotion of personhood in long-term care and other settings..

A second finding was that the family caregivers observed the nursing home staff who demonstrated respect for the personhood of individuals with dementia and care that showed a lack of respect. Caregivers closely observed staff communication, verbal and nonverbal, with the person with dementia. In their narratives, they identified staff who respected the personhood of residents with dementia and staff who discounted the person. For example, there were stories of nurses who never smiled, never talked to residents, and who never bothered to get to know them, their family member or other residents with dementia. They also identified administrators and nursing directors who role-modeled behaviors that promoted personhood and who encouraged interactions with the residents. At one facility there was clearly an expectation for everyone in the facility to know the new resident's face and name and to welcome them. The caregivers, as consumers and observers, can advise administrators and nurses on processes to improve patient care that promotes personhood.

A next step for nurses is to consider best practices for teaching, modeling, and engaging staff in the provision of person-centered care that acknowledges personhood. However, limited research exists on whether person-centered care that respects personhood can be taught. Fisher and Wallhagen¹⁶ found that nurse assistants' views of their residents might be modifiable. In their study, nurse assistants had three kinds of views of residents. Some viewed patients as fictive-kin and regarded them as they regarded older family members. A second group responded to residents as commodities to be cleaned, dressed, and bathed according to a checklist. A third group viewed residents as autonomous individuals who served as partners in their care. Interestingly, nurse assistants in a particular facility tended to share the same dominant view¹⁶. This suggests that views may be modifiable and may be linked to the culture of care established by administration¹⁶.

If respect for personhood is modifiable, the next question is how to promote person-centered care and respect for personhood by staff in long-term care settings. Family caregivers may be helpful in teaching staff about personhood. For example, the use of caregiver stories, such as those provided in this article, provide specific exemplars for discussion during an educational activity. Other interventions for preservation of personhood in the long-term care setting include encouraging family members to bring in photos and personal items, and to share their knowledge⁹ about the routines, moods, behaviors, wants, and needs of the person with dementia. Promising techniques to create or enhance awareness of the personhood of residents with dementia and foster relationships include the use of drama¹⁷, storytelling¹⁸, and metaphors¹⁹. Support for the use of stories to help staff “reengage” and “reconnect” with the meanings of their practice and with their residents comes from the work of Benner²⁰. Another technique that has potential is the use of life history collages²¹. Buron exposed long-term care staff to life history collages for 4 weeks and the exposure increased knowledge about the individual though it did not have a significant effect on perceptions of individualized and person-centered care [ENREF 34](#)²¹. Another approach that has been used is to assign nursing students, as part of their clinical experience, to write a narrative plan of care from the perspective of the nursing home resident²². Further research on these interventions and others is important to assure quality of life for individuals with dementia in long-term care.

Finally, there are several studies that offer guidance on how to disseminate best practices in the care of older adults to staff and these may provide direction on how to teach and engage staff in providing person-centered care that supports personhood. For instance, intentionally addressing the topic of person-centered care using a variety of instructional techniques may help staff incorporate care that acknowledges personhood. This has been shown to be effective when teaching about other topics. For example, Teresi et al. (2012) found that didactic instruction on resident-to-resident elder mistreatment, a film with skits and discussion of exemplars on the topic, and detailed instruction on reporting guidelines increased staff knowledge and reporting of incidents²³. In addition to intentionally addressing the topic of personhood through educational activities, involvement of all staff in identifying and addressing ways to promote person-centered care may promote adoption. This intervention is supported by a study of factors that lead to full adoption of quality improvement activities. Rantz et al. (2013)²⁴ found that focusing on specific care topics, along with the staff forming and working as a team, and involvement of nursing administrators or the Director of Nursing was associated with “full” adoption and likely sustainment of the activities. Effective teams are described as those that promote participation by all members, written communication about team meetings, and ongoing discussion of the clinical topics that are an issue at the time. In summary, while there are studies to guide dissemination of best practices in the care of older adults, little is known about whether these are effective in guiding care that addresses personhood. This study is the beginning of an effort to set the standard of effective care with a conscious effort to promote and maintain the personhood of persons with dementia.

Limitations

A limitation of this research is that only the perspectives of involved family caregivers who self-selected to participate were included. This may affect the generalizability of the study findings. Also, the study did not include caregivers who were not close relatives and these individuals might have experiences that differ from those of adult daughters and spouses. Further, the mostly Caucasian, non-Hispanic caregivers in this study were recruited from one geographic area in the Midwest so their experiences may differ from those of caregivers in other areas and with other racial and ethnic backgrounds. Finally, specific questions about personhood and person-centered care practices were not included in the interview guides but emerged from stories of the caregivers' everyday practices in the long-term care facility. Intentionally exploring personhood and person-centered care practices may have revealed activities that were not mentioned during the interviews.

CONCLUSIONS

In summary, these family caregivers' experiences in the long-term care setting revealed both practices that respect and practices that devalue the personhood of individuals with advanced dementia. The family caregivers were attuned to the moods, needs, desires, and patterns of behavior of loved ones, and they appreciated the practices of long-term care staff that were attuned to the personhood of residents with dementia. They also recognized when this care was not happening. Observations by family caregivers of the nursing care of residents with dementia provide insight into the culture of care within long term care institutions and suggest implications for nursing care. Evidence suggests that recognition of personhood can be taught and a number of interventions show promise. The family caregivers' observations inform current nursing practice and may be useful for designing future interventions to address respect for personhood.

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Table 1

Participants' Characteristics

Variable	Spouses N (%)	Adult daughters N (%)
Relationship	9 (60)	6 (40)
Education		
High school	2 (13)	0 (0)
Some college	2 (13)	2 (13)
Bachelor's degree	2 (13)	2 (13)
Master's degree or higher	3 (20)	2 (13)
Work status		
Currently working	2 (13)	4 (27)
Retired or with disability	7 (47)	2 (13)
Self –rating of health		
Excellent	2 (13)	1 (7)
Very good	5 (33)	3 (20)
Good	0 (0)	0 (0)
Fair	1 (7)	2 (13)
Poor	1 (7)	0 (0)
Annual household income		
\$25,000-49,999	4 (27)	1 (7)
\$50,000-74,999	4 (27)	2 (13)
\$75,000-98,999	0 (0)	1 (7)
>\$99,000	0 (0)	2 (13)
Refused	1 (7)	0 (0)

Table 2

Sample of interview questions and probes

<ul style="list-style-type: none"> Describe a recent incident at the care facility that was difficult, annoying or confusing for you. <p>Probes if needed:</p> <ul style="list-style-type: none"> ☐ Tell me what happened. ☐ What led up to the situation? ☐ What were your feelings and thoughts about it? ☐ What did you do? ☐ What were your priorities? ☐ What else did you consider doing? ☐ Who else was involved in this situation? ☐ Were they a help or a hindrance? ☐ How was the situation resolved? How did you feel then? ☐ Looking back on it now, is there anything you would have done differently? ☐ Is there anything else you would like to add that I have not already asked? <ul style="list-style-type: none"> Describe a situation at the care facility that you remember with a lot of pleasure, or that was especially meaningful or satisfying to you (<i>Above probes used as needed</i>) Have you been surprised by anything that happened during or because of placement of your spouse/ parent? (<i>Above probes used as needed</i>)
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