

Perspectives of Assisted Living Facility Caregivers*

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Abstract:

This qualitative study describes the kinds of knowledge used by caregivers when caring for older adults with dementia residing in assisted living facilities. Five focus groups were conducted with a total of 23 caregivers from both small and large facilities. Two categories of knowledge were described: behavior-centered knowledge and person-centered knowledge. Behavior-centered knowledge focuses on strategies needed to manage behaviors, whereas person-centered knowledge focuses on the needs of the person exhibiting the behavior. Recommendations about the role of gerontological nurses and the training of caregivers in assisted living facilities are provided.

Article:

The incidence of Alzheimer's disease and dementia continues to rise: More than 4 million Americans have the disease, and the prevalence doubles for every 5-year age group older than age 65 (National Institute on Aging, 2005). Although most care is provided by family and friends, the need for long-term care grows as impairments increase. Assisted living facilities have become an alternative to nursing homes as long-term care settings for older adults with dementia. Little is known about the level of knowledge of caregivers working in assisted living facilities, particularly about their knowledge and ability to care for residents exhibiting behavioral symptoms of dementia. The purpose of this study was to identify the kinds of knowledge used by assisted living facility caregivers who care for older adults with dementia.

BACKGROUND

Assisted living facilities may be small (6 or fewer beds) or large (50 to 100 beds). The philosophy of assisted living facilities is to promote residents' independence, meet their needs, and allow them to age in place in a homelike environment. The National Center for Assisted Living (NCAL) estimates that the number of residents in assisted living facilities in the United States is more than 900,000 (NCAL, 2006a). In addition, 42% to 50% of residents in assisted living facilities have dementia, and 34% of them exhibit behavioral symptoms of dementia at least once per week (Gruber-Baldini, Boustani, Sloane, & Zimmerman, 2004). Caregivers at assisted living facilities are challenged to meet the basic needs of these residents and to keep them safe from harm.

The 24-hour care and supervision of residents in assisted living facilities is provided by personal care aides, although some may be certified nursing assistants (CNAs) or have worked as home health aides (Paraprofessional Healthcare Institute, 2006). Most states require some kind of general orientation and annual inservice training, but training requirements vary across states. For example, some states stipulate the minimum

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age of caregivers and provide no specific training, whereas others require an 80-hour training course and yearly inservices (NCAL, 2006b). In North Carolina assisted living facilities, Level 1 aides caring for residents who need assistance with only one activity of daily living (ADL) require only 25 hours of training; Level 2 aides caring for residents who need assistance with two or more ADLs require a 75-hour basic training. Staff must be trained as CNAs if they are caring for residents who require skilled level care (e.g., those with gastric tubes, dermal ulcers). In addition to providing direct care, caregivers who own and operate small assisted living facilities often reside onsite, hire and train staff, and do the cleaning, laundry, shopping, and cooking.

Much of caregivers' knowledge about caring for people with dementia comes from life experiences or is learned on the job. Identifying this knowledge can provide a foundation for the development of training activities and materials that caregivers with limited health training and who are from diverse sociocultural backgrounds will understand. Thus, the purpose of this research was to examine the knowledge and strategies used by caregivers working with older adults with dementia in small and large assisted living facilities.

METHOD

This was an exploratory, qualitative study using focus groups as the method of data collection. Focus groups were selected to allow for interaction among the participants in a safe environment, to encourage participation of caregivers who might be reluctant to be interviewed on their own or who feel as though they have little to say, and because focus groups have been found to be appropriate for groups that may feel disempowered (Kitzinger, 1995).

Settings and Sample

Recruitment began after institutional review board approval. Purposive theoretical sampling was used to ensure that participants who were selected reflected a range of views (Kitzinger, 1995) and to identify caregivers from both small and large assisted living facilities. For small facilities, officers of the state provider organization identified caregiver owners in three counties who might be willing to participate and notified them that they would be receiving a letter from the researchers. A recruitment letter was sent with a postage paid postcard to return if they did not wish to participate. The researchers then telephoned the owners to discuss the project and obtain verbal participation consent. Follow-up letters were sent to confirm the date, time, and place of the focus group.

For the large facilities, the supervisor of the county department that monitored the facilities was asked to identify administrators who might allow a focus group in the facility. After receiving administrators' permission, focus group recruitment flyers were posted, and caregivers interested in participating placed their names in a sealed envelope for the researchers.

The principal investigator, an African American woman, was well known in the caregiver community, which was primarily composed of

TABLE**CHARACTERISTICS OF SAMPLE**

Focus Group	Facility Size	Median Age (Range)	Median Years of Experience (Range)	Level of Basic Training: Level 1 or Level 2	Level of Basic Training: CNA
A (n = 6)	Small	55.5 (43 to 66)	18.5 (10 to 35)	4	2
B (n = 3)	Small	55 (45 to 55)	9 (8 to 27)	0	3
C (n = 4)	Small	55 (51 to 59)	15.3 (8 to 20)	2	2
D (n = 4)	Large (dementia unit)	54.5 (45 to 56)	3.3 (1.6 to 15)	1	3
E (n = 6)	Large	31.5 (21 to 54)	6.9 (0.17 to 10)	0	6

Notes. Small = < 7 beds; Large = 50 to 70 beds.

CNA = certified nursing assistant.

Level 1 training = 25 hours; Level 2 training = 75 hours.

African American women, through her previous research and educational endeavors with provider organizations. Her prior work enabled her to be seen as a part of the communities in which the recruitment was conducted, which is believed to be key to the success of the study. Previous focus group research has shown that participants' comfort level is enhanced by matching facilitators to the gender and ethnicity of group members (McQuiston & Gordon, 2000).

The sample was composed of five focus groups and a total of 23 participants. The Table displays the number of participants in each group, the size of the facility, and the age, experience, and training of each group's participants. Three focus groups were composed of caregivers who were also owners or administrators of small assisted living facilities. Two focus groups were composed of caregivers from large facilities, one with 75 beds and the other from a dementia care unit within a 50-bed facility. Ages of the caregivers ranged from 21 to 66, with a median age of 53. There was only one male participant, and he was the husband of another participant from a small facility.

The groups were similar in the percentages of African American participants (small facilities = 69%; large facilities = 70%). Fifty-four percent of the participants from the small facilities and 90% of those from the large facilities were CNAs. Forty-six percent of the participants from small facilities had some college education, but for participants from the large facilities, the highest level of education was high school. The focus group participants from small facilities also had more experience working in long-term care (14 years versus 5 years for the groups at large facilities). The Table also designates the level of participants' basic training, with categories for those who had completed the 25-hour course (Level 1), 75-hour course (Level 2), or had more advanced training as CNAs.

Procedures

Procedures were based on Kitzinger's (1995), Gibbs' (1997), and Mansell, Bennett, Northway, Mead, and Moseley's (2004) recommendations to ensure a high level of interaction between focus group participants. The focus groups of caregivers from the small facilities were held in a meeting room at the local convention center, a library's community room, and a church. Focus groups for the large facilities were held in the facilities' activity rooms.

At the beginning of each session, the purpose, ground rules for discussion (e.g., being respectful of different opinions, allowing everyone to talk), the use of audiotape, and written informed consent (which included permission to audiotape) were reviewed and signed consent forms collected. The moderator (J.R.) used the same semi-structured interview guide with all groups; the guide was distributed to all participants at the beginning of each session. Sample questions included:

- “Describe how you work with people with dementia.”
- “Are there behaviors or actions of residents that you or staff have trouble dealing with?”
- “How do you handle them?”

The assistant moderator (D.D.K.) wrote field notes during the session, including documenting who was speaking. At the end of each session, the assistant moderator summarized the key points and gave participants an opportunity to clarify, verify, or modify their perceptions of the key points. The summaries were audio-taped, and the participants’ reactions to these summaries were included in the data analysis.

Each focus group lasted approximately 1 hour, with the last 10 minutes used for verification. Refreshments were provided during the sessions, and each participant received a \$25 gift certificate to a national retail store as a token of appreciation. Immediately after the sessions, the moderator and assistant moderator checked the audiotapes for clarity and debriefed. Field notes about group dynamics were kept during these debriefings and were included in the data analysis.

Data Preparation and Analysis

Focus group data preparation and analysis was conducted using Kreuger’s (2000) guidelines. The audiotaped recordings were transcribed after each focus group session, and each tape was compared with the field notes, to verify the accuracy of the transcription, make corrections, and supply missing data. The researchers met between group sessions and identified areas from the interview guides that needed further exploration in future groups. Between focus groups, the researchers also met with expert qualitative researchers, initially to review the quality and depth of the data, identify early themes, and confirm directions for future focus groups. As the research progressed, these meetings focused on data categorization and themes so that findings from later groups could be used to confirm or refute categories and themes from earlier groups.

The unit of analysis was the group, and using Kreuger’s (2000) recommendations for analyzing focus group data, the researchers first reflected on each transcript individually, identified themes and extracted significant statements and their meanings, and then manually coded responses. The researchers then met to discuss the coding and coding rules and assess the degree of agreement. NVivo software, version 2, (QSR International Pty Ltd., 2002) was used to facilitate coding and sorting of text, and data were sorted and displayed in a matrix to facilitate comparison of themes across groups. Theme development was initiated by each researcher individually and then reviewed by the second until unanimous agreement was achieved.

One theme that emerged early on was the differing kinds of caregiver knowledge. Sentences reflecting similar kinds of knowledge were then extracted and grouped to determine whether the sentences were the same or similar. This led to deeper understanding and insights. The researchers agreed that there were two categories of knowledge and agreed on rules for including participants’ statements in one or the other of these categories.

RESULTS

Two categories of knowledge were described by these groups: behavior-centered knowledge and person-centered knowledge. However, this knowledge may not be clearly apparent to other health care providers, due to the caregivers’ verbal grammatical errors. To ensure that the findings remained grounded in the words of the participants, their grammatical errors were left in the statements for this article.

Behavior-centered Knowledge

Behavior-centered knowledge involved knowing recommended approaches for use with a specific behavioral symptom of dementia. One focus of behavior-centered knowledge was on stopping the behavioral symptoms of dementia that often occur during care tasks, such as bathing or dressing, so the task can be completed. For example, one caregiver said, “You have to speak in a calm voice, move slow, and if they are agitated, back off.”

Approaches such as staying calm when interacting with the resident and using distraction helped caregivers obtain cooperation from the resident, which in turn made the caregivers' work easier.

For example, agitation is a behavioral symptom that residents frequently display when being assisted with bathing. One caregiver's approach was to not force the bath and to try again at a later time with a modified interaction style. She stated, "I find if they want to fight at that particular time, go away, come back later and approach them with a different attitude and they may or may not [cooperate], but you go away and come back later."

Another behavioral symptom of dementia is eloping, as described by Algase et al. (2004). Many individuals with dementia try to leave the building, which presents the concerning possibility of the person being injured or lost. One caregiver used redirection to prevent eloping behavior:

If you do have one that is just mind-set that they [are] gonna go, go, go, you can pretty much redirect them, and after a while, they'll redirect. With you redirecting them not to go out that door, eventually they gonna drop it. They're not gonna do it.

With experience, caregivers learned that their approach influenced residents' behavior. Noting that some actions facilitated accomplishment of the care task and other actions hindered it, caregivers modified their strategies over time. One caregiver, who was also a facility owner, said:

The staff that I've had in the past, they'll say: "No, you can't go out." That doesn't work. I have learned that just walk with them, "Let's go for a walk." And it helps them.

Another caregiver said:

You can say, "Well, if you can take your bath twice this week, you can [wash your hands and face] the rest [of the days in the week]." And if you do it like that, they will overcome it. But you have to take it easy, you just can't say, "OK, you going to get in this tub and you're going get in it today." You might get them in there, but I guarantee you won't get them out of those clothes.

Person-centered Knowledge

The second kind of knowledge was person centered. All of the groups except one used person-centered knowledge. One caregiver said, "Know the residents like you know the back of your hand. I know them like the back of my hand." These caregivers looked beyond the behaviors to see the person and attempted to understand the meaning of the behaviors for the resident. Person-centered knowledge included the recognition that residents' behavior was influenced not only by the disease process of dementia, but also by their feelings, social and emotional needs, and past experiences. For example, two caregivers pointed out that the approaches they used for residents who were afraid of the water when bathing were different than the approaches used for residents who had forgotten how to take a bath.

Person-centered knowledge was enhanced by teamwork. New caregivers, who did not know the residents, learned to ask coworkers how the residents might react. Caregivers learned that an approach might vary by person and that one resident might need a different approach than others. One participant noted, "We've got to be a team." Another stated, "If you are new on the job, talk to coworkers. Ask, 'How do I handle this one [resident]?'"

Caregivers with person-centered knowledge recognized the full range of the residents' psychosocial needs. Their knowledge that the need for autonomy, dignity, respect, and self-esteem does not diminish with age or cognitive impairment was demonstrated by the following comments: "This is a human being with a real problem ... that you may have someday...so treat this person with all the dignity and respect that you possibly can," and "Dignity means a lot to them ... and vanity...so that's when we come into the picture, we put on the lipstick... make-up... comb their hair."

Caregivers also understood that residents' life histories may influence the behavioral symptoms of dementia. One participant noted:

Residents will hit you, cuss you, bite you, spit at you, say things you think they're gearing directly at you, but at that moment, wherever their minds are at, you may look like somebody in their past that ticked them off [angered them]. It's not you, it's wherever they are at.

These caregivers stated that they used residents' life histories to anticipate their clients' needs and to prevent the behavioral symptoms of dementia.

The four groups that described person-centered knowledge also talked about the attachments they had developed to their residents. These attachments were described as very personal involvements or even as viewing the resident as family. Remarks exemplifying these sentiments included:

- “These people have become a part of me, even though we say ‘Don’t get too involved.’”
- “These clients are like our family, they are part of us.”
- “This is our grandmas and our grandpas.”

The caregivers loved the residents and explained how the residents loved them. Person-centered knowledge can be summarized by the following caregiver's statements:

You need to know your residents to where ... you know them well enough that you might not be able to put your finger on it, but when you see them walking down the hall, you know instantly there's something, something's not right.

DISCUSSION

These assisted living facility caregivers described two categories of knowledge used when caring for residents with dementia—behavior-centered and person-centered knowledge. Liaschenko and Fisher (1999) found that nurses used three types of knowledge in their practice: knowledge of the case, knowledge of the patient, and knowledge of the person. Knowledge of the case, which includes typical clinical interventions, is similar to these caregivers' behavior-centered knowledge, which focused on strategies to diminish or eliminate specific behaviors in order to complete care tasks. With these assisted living facility caregivers, person-centered knowledge was a combination of Liaschenko and Fisher's (1999) knowledge of the patient (knowledge of the disease) and knowledge of the person (knowledge of the personal biography).

All of the groups except one used person-centered knowledge. The group that did not demonstrate person-centered knowledge included members who were considerably younger and had less experience than the members of any of the other groups. Radwin's (1996) review of the literature about the nursing concept of “knowing the patient” and her subsequent grounded theory study of expert nurses' strategies in clinical decision making (1998) found that experience was related to knowing the patient. Nurses who were experienced were comfortable with their role and could focus on the patient. Benner, Tanner, and Chesla (1992) also found that more experienced nurses (experts) put the primary emphasis on patient needs, whereas beginning nurses focused on care tasks.

The assisted living facility caregivers who talked about person-centered knowledge also described an attachment to the residents. Similarly, Radwin (1996) found in her review of the literature that a sense of closeness was related to “knowing the patient.” Radwin also found that sustained contact was related to nurses' knowing the patient. Of this study's four focus groups demonstrating person-centered knowledge, three were composed of caregivers from facilities with fewer than seven beds, and the fourth was composed of caregivers from a specialized dementia unit within a large facility. The caregivers in the small facilities had fewer residents for whom to care, which allowed more contact time per resident. Because some of these caregivers were also the owners of the facility, thereby living in the same home, their contact lasted longer than an 8-hour shift. The fourth group, from the specialized dementia unit, also cared for a small number of residents, which allowed

more contact. Sustained contact facilitates caregivers' ability to maintain interactive communication, which is a key aspect of working with residents whose ability to communicate is compromised. The fifth focus group, whose participants did not describe person-centered knowledge, was from a large facility. Large facilities usually have a higher ratio of caregivers to residents and less sustained contact. A key finding of this study is that all groups—whether composed of owner-operators of small facilities or of employees of large facilities—were passionate about training newly hired caregivers about the kinds of knowledge needed to care for residents with dementia.

LIMITATIONS

One limitation of this study, as well as a general limitation of the focus group and theoretical sampling methods (Kitzinger, 1995), is possible bias due to participants' not representing the majority of assisted living facility caregivers. Future studies could systematically examine the knowledge caregivers use in their care of residents with dementia. The relationship of category of knowledge with caregiver experience, resident attachment, and resident outcomes could also be explored.

CONCLUSION AND NURSING IMPLICATIONS

The focus group members described two categories of knowledge that guided their care of residents with dementia: behavior-centered knowledge and person-centered knowledge. Behavior-centered knowledge is the information that has traditionally been taught to all levels of caregivers. Caregivers noted that their person-centered knowledge came from experience; they did not mention learning about the importance of "knowing the person" from their training or from continuing education. This is not surprising; the short training programs generally mandated for these caregivers emphasize the completion of tasks associated with ADLs. However, because adults in assisted living facilities are aging in place and developing dementia and other chronic illnesses, their care has become more complex. One recommendation for preventing or reducing dementia-related behaviors is to know a resident well enough to determine the stimulus behind the behavior (Landreville, Dicaire, Verreault, & Levesque, 2005). Individualized care is also likely to increase residents' quality of life.

Assisted living facility caregivers need to be taught how to include residents' life stories in their care plans, because knowing these life stories may help the staff understand why residents are exhibiting behavioral symptoms of dementia. For example, one of the caregivers at a large facility stated how it was important to know when her resident's husband had passed away, because the resident's behavioral symptoms increased every year for the same 2 months that corresponded to his death. In another example, an owner of a small facility stated that one of her residents was afraid of bath suds because she had been abused in her marriage and the suds reminded her of a man in the tub.

These are just two of many examples participants mentioned that demonstrate how knowing residents' life stories may be used to gain trust and prevent behavioral symptoms of dementia. One caregiver said that knowing a resident had always liked drinking cola or wearing a bow in her hair allowed her to provide the cola or bow, thus individualizing care and maintaining resident dignity. Caregivers must be taught to focus on the possibility of forming reciprocal relationships with residents rather than maintaining artificial boundaries, which may prevent holistic care and keep caregivers from experiencing the benefits of knowing the person. Parsons, Simmons, Penn, and Furlough's (2003) study of 550 nursing home nursing assistants found that nursing assistants identified their relationship with the resident as the major reason for staying with the job. This is crucial, as the turnover rate of CNAs is approximately 71% each year (American Health Care Association, 2003).

As residents age in place in assisted living facilities, with many residents becoming frail and vulnerable, their care could be enhanced by gerontological nursing involvement. Gerontological nurses could play a primary role in teaching how to individualize care and could serve as role models by working directly with caregivers. They can develop educational materials and provide consultation.

In addition, assisted living facility caregivers who have learned to use person-centered knowledge in their residents' care must be identified and recognized. These experienced caregivers could be taught to be peer coaches for less experienced caregivers. Nurses and peer coaches could teach new caregivers how to know their residents and how to use this information to develop individualized strategies, rather than just memorize a set of behavioral approaches. The behavioral approaches need to be taught as basic knowledge, and then caregivers must learn how getting to know the resident will improve not only the residents' quality of life, but also their own job satisfaction. Good care involves more than reacting to behaviors. Recognizing and anticipating the individual needs of residents with dementia is the foundation for individualized and high-quality care.

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