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Direct Care Workers' Views on Improving Care for People with Dementia in Residential Setting

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Abstract

Background: Dementia is a brain disorder affecting memory, mood, personality and behaviour. An estimated 5 million people in the United States (US) have dementia and the vast majority of elders in residential care are cognitively impaired. Direct care workers, Certified Nursing Assistant (CNAs) and Care Assistants (CAs), provide most of the hands-on assistance for these residents. However, little is known about their views on providing care and ways to improve it.

Aims: This study examined the knowledge base, care practices and recommendations for quality improvement of direct care workers regarding residents with dementia in residential long-term care facilities.

Sample: The population consisted of 69 CNAs and 22 CAs, comprising 15 focus groups, from 32 facilities in Georgia in the Southeastern United States (US).

Methods: Qualitative interviews were conducted with direct care workers. Experts in elder care, including physicians, nurses, and CNAs, provided input on the script. Trained facilitators guided sessions. Extensive content analysis was used to identify themes related to dementia care.

Results: Dementia affected the majority of residents carried for by CNAs and nearly all of those of CAs. Half of all workers reported that they were not formally notified by their facility when a resident had dementia. Most staff identified cognitively impaired residents based on observation. They used a range of indicators, including changes in mood and facial impressions with speech being the most common sign. All were consistent with physician diagnostic criteria for dementia. The main challenges in providing care were: general issues related to memory loss, such as facility orientation; difficulties completing activities of daily living (ADLs); becoming frustrated with patients, and safety issues, including physical threats to staff and other residents from cognitively impaired residents. The additional time required to monitor and care for these residents was stressed. Groups had a wide-ranging recommendation to improve care with the most common being staff monitoring their own behaviour. Training was viewed as valuable, but needed to be realistic, with one focus being medication.

Conclusion: The findings here show that direct care workers have a wealth of information on how to provide quality care and identify targets ripe for QI. Those designing training and QI programs would benefit from incorporating their input.

Keywords: Certified nursing assistants; Care assistants; Dementia care; Quality improvement; Nursing homes; Assisted living facilities

Introduction

According to the World Health Organization, 47.5 million people have dementia world-wide, with 700,000 new cases each year [1]. In the US, an estimated 5 million people are affected by dementia and many live-in institutions [2].

The majority of residential long-term care is provided in two settings: nursing homes (NHs) and assisted living facilities (ALFs). NHs provide round-the-clock care and supervision and skilled nursing care as need. ALFs provide assistance with activities of daily living (ADL) and medication supervision. ALF residents must be able to ambulate on their own and not need skilled nursing services.

In 2014 1.4 million people lived in NHs and 835,200 in ALFs [3]. Over half of NH residents had a dementia diagnosis. In ALFs 40% to 80% of residents are estimated to have dementia; values range as many residents may not be diagnosed in these settings [4,5].

Given its prevalence, burden on caregivers and long-standing concerns about quality of care, particularly understaffing, dementia has received substantial attention from policy-makers, researchers and entities that pay for long-term care [6,7]. Medicare, the primary insurer for those age

65+, is particularly concerned about cost. In 2008, total per person payments, $43,847, from all sources for health care and long-term care for those with dementia were triple those without it [8].

Much research has gone into the best way to care for these residents [9]. The main care models investigated have been developed from community interventions with dyad pairs of informal caregivers [10]. Others have worked from the health care provider side, such as the primary care medical home model which seeks to coordinate care [11]. Neither takes the perspective of care within the facility.

One new model, considered innovative by Medicare, involves registered nursing rotating between facilities and working with consultant advanced practice nurses to help avoid hospitalizations [12]. While nursing is a key part of resident care, the role of direct care workers has been ignored in medically-led interventions [13].

A few NH interventions have focused on daily care practices, but the models are time-consuming and are generally impractical given current staffing levels [14]. Further, the ALFs setting has yet to be investigated [15].

Some research has explored the attitudes of NH direct care staff in managing pain, while two recent articles have explored the attitudes of direct care staff in NHs and ALFs involving falls and incontinence care [16-18]. They have yet to inform quality improvement (QI) interventions.

Including direct care workers' input any initiative is critical for its success. Direct care workers, CNAs and CAs make up 82% of staff in (ALFs) and 64% of staff in NHs [3]. This study interviewed direct care workers about their knowledge base, care practices and best practice recommendations regarding providing assistance to residents with dementia to inform QI programs in residential long-term care facilities.

Workers from Georgia comprised the sample. Within the state, CNAs tend to work in NHs and are required to have a high school education and some form of post-secondary nursing instruction. They must complete 85 hours of course work and 24 hours of supervised on-the-job instruction and they pass an exam to be certified [19].

CAs, on the other hand, tend to work in ALFs. They are required to have 24 hours of on-the-job training and 18 hours of continuing education every year. The staff-to-resident, at one to fifteen, is far higher than in nursing homes [20].

Methods

The study was conducted using established standard qualitative research methods. Using this approach, topics are investigated systematically to generate new knowledge from stakeholders informed about the subject which can ultimately inform quantitative analysis [21]. The descriptive subtype employed here focused on the knowledge base, care practices and recommendations for care improvement of direct care workers in relation to dementia, we categorized general themes about them through content analysis [22].

The study was sponsored by the Emory Center for Health in Aging (ECHA), along with a consortium of affiliated long-term care providers interested in QI, all located in Atlanta, Georgia. Following a review of ethical and regulatory considerations, the Institutional Review Board at Emory University in Atlanta, Georgia approved the project.

Researchers (D.Y.R. and V.P.) developed the script in consultation with clinical experts, including physicians, nurses, social workers and CNAs. It was reviewed by representatives from the Atlanta Area Alzheimer's Association for content and local health educators for comprehension levels and language.

It was pilot tested with several CNAs and CAs from a single facility affiliated with the ECHA, the medical arm of the university. Questions were modified based on feedback from this group. A copy of the script is available from the corresponding author (V.P.).

Sample

The sample of CAs and CNAs was drawn from 22 nursing homes and 10 ALFs; all of which were facilities collaborating on QI projects with the ECHA. Participants (n=91) volunteered or were nominated by their facility. Fifteen focus groups were held: five in a metropolitan area (the state capitol) and two in semi-urban/rural areas. Focus group size ranged from 3 to 10 participants with multiple groups held at three of the sites. Forty-two participants were from facilities outside the capitol and 25% worked in ALFs.

Data collection tools

Participants answered a short questionnaire about themselves. Based on feedback during the script review, they were informed that, for the discussion, dementia referred to cognitively impaired residents as well as those formally diagnosed with Alzheimer's disease.

Following standard qualitative research methods, the discussion began with an open-ended question asking about general health issues affecting residents. Subsequent questions focused on: prevalence of dementia, how residents with dementia are identified, facility care practices and effective ways to provide care for residents with dementia. The results are organized topically and follow the sequences of questions asked during the interview. Percentages represent the number of responses divided by the total number of groups (n=15).

Results

Ninety-five percent of respondents were female and the mean age of the group was 39 (s.d. 11.4). CNAs had worked significantly longer in their current place of employment than CAs, 6.8 (0.06-36) years compared to 2.8 years (0.08–11) ($p<0.01$), while both groups had worked in the field an average of 9.5 (0.08-36) years.

Prevalence of dementia among residents

Dementia was the most prevalent condition reported when CNA or CA groups discussed what health problems they encountered among residents under their care. Among CNAs, 60% noted the residents suffered dementia, while CAs reported it affected all residents that they care for.

One group, comprised of both CNAs and CAs noted the progressive incapacity resulting from dementia and its impact on memory, mood and the manifestation of certain behaviours:

"I mean physically they're okay but mentally they don't have it together. Sometimes they have a lot of mood changes. You know, that's one minute they're okay and the next minute they're about to fight and then sometimes they'll get depressed and they won't want to say anything (CNA, Focus Group 12)."

Identifying residents with dementia

In terms of identifying residents with dementia, several groups mentioned that they were told by staff when the resident moved in and/or informed by a family member. Sixty percent read it in resident care plans, while all groups watched for signs of dementia.

Table 1 shows the most common signs identified by category.

Table 1 Signs of dementia observed by general category by certified nursing assistants and care assistants.

Sign of dementia	Certified nursing assistant groups (n=7)	Care assistant groups (n=8)	Groups reporting behavior	Percent of total groups (n=15)
Speech-related issues	5	8	13	87%
General forgetfulness	5	5	10	77%
Problems related to activities of daily living-related	2	8	10	77%

They discussed a wide range of indicators that helped them identify demented residents, from facial expressions to dressing. One CA described:

"You have to learn. They keep asking the same thing over and over; And they're constantly calling you someone else's name. Let's say they're feeding themselves, they might be sticking a straw or something, instead of their spoon or fork they might be eating with their straw, or dipping their hands in everything. So, you can pick up on the people who really have memory loss (CA, Focus Group 10)."

Speech-related problems, including repeating things, using the wrong word, and talking incoherently, were noted by 87% of groups. General forgetfulness, in terms of forgetting their names and problems navigating the facility, was mentioned by both CAs and CNAs in equal numbers. Problems in performing ADLs were noted as a sign, but mentioned far more frequently by CAs where residents tend to be more mobile.

Job complications resulting from residents having dementia

Residents with dementia created significant difficulties in terms of performing daily job tasks compared to those without dementia. A major theme was the frustration arising from the inability to communicate with residents.

Sixty percent of the groups discussed the extra time it took to perform care activities, such as eating, dressing, and brushing teeth. One commented:

"You know we are on a time schedule of course like any other job and when you can't get them to do it,.... It's all harder. It's easy for you to dress them yourself.... and then they are refusing it and pushing it away. It makes you work harder. (CA, Focus Group 6)."

Safety concerns were also an important theme. Combative behaviour, often in relation to ADLs, was mentioned by three of the groups and stressed as the most difficult to manage. One CNA gave the example of dressing:

"Yesterday morning I had a resident I had to get (dressed) and he was swinging, he was kicking. I mean it took us almost an hour just to get his clothes on…He was riled, he was fighting. But later after breakfast he was fine. (CNA, Focus Group 2)."

In some instances, behaviours endangered staff. One CA reported:

"I used to wear a lot of jewelry, and so this lady… she snuck up behind me and did like this to my neck. Which I had the shower thing like this, and then my other patient fell out in the shower room. When I woke up I was in the emergency room...It's just because she couldn't stand her niece, and she thought I was her niece.... I was about to quit this place because I CNA't take it. But I stayed with them and everything, but finally she passed away (CA, Focus Group 10)."

Wandering was mentioned by 45% of the groups as a problem and how these residents must be supervised closely for their own safety and also that of other residents. Night wanderers were identified as particularly problematic as lack of sleep can contribute to behaviour issues. One CA gave the example:

"…He was determined– you know, we're on the third floor and he CNA go look out on the balcony and he says, my house is right over there and I'm going home. So, he…lifted the window up, put one foot out. He was half way out of the

window. But you know, you're like– I was like oh Lord I'm gonna kill myself and I'm gonna kill him… (CA, Focus Group 3)."

Another CNA noted:

"One lady she walks around, and she went into some other patient's room. She tried to smother her purposely, so we had to restrain her. Because one time we got in there, and she had the covers and the pillows on her face." (CNA, Focus Group 10).

Staff training and dementia care

Dementia training was deemed very important by both staff groups. One third of the groups reported that their employers did not provide training. Many commented that education was what helped them understand what having dementia meant. One commented:

"…So you're trained how to care for the dementia, and you're meant to understand, you're put in their shoes. If you know whom you're dealing with then you know how to help them. Because before I was trained I didn't know what was there, what they are, and what they feel, and the reason why they behave that way (CA, Focus Group 5)."

Sixty percent of each group wanted continuous training and enjoyed in-services provided by outside experts. They also mentioned the benefits of hands-on training and role-playing, but one group noted the need for realism stating:

"They show us stuff that don't come close to what we really have (CNA, Focus Group 1)."

Two groups of CNAs stressed the need for education in psychiatric medication and possible drugs side-effects.

Advice on caring for Alzheimer's and dementia residents

All direct care workers had extensive advice about ways to provide quality care for residents with dementia, most of it based on experience. **Table 2** summarizes the top four areas mentioned.

Table 2 Certified nursing assistant and care assistant advice on constructive ways to care for residents with dementia.

Recommendation category	Certified nursing assistant groups	Care assistant groups	Total	Percentage (out of 15)
Don't fight	8	7	15	100%
Using touch or voice	9	5	14	93%
Staff patience	6	5	11	73%
Medication for residents	5	4	9	60%
Keep resident busy with activities they like/Distract them and encourage interactions with other residents	6	3	9	53%
Know the resident/family	1	4	5	33%

Overwhelmingly recommendations related to staff behaviour and all groups mentioned the need to avoid fighting with residents. Many reinforced the important of walking away if needed and asking for help.

Ninety-three percent of groups stressed the importance of using touch or a soothing voice when working with residents, particularly to calm them down. They viewed talking them through activities as critical, even though it could be time-consuming. One CNA commented:

"You've got to let them know what you're doing, and walk them through it. They'll ask what are you doing, 'you didn't tell me you were going to do this or that', all through that space... it's about 15 minutes with them…Because some of them they can't comprehend me telling them, we've got to go to another resident and take care of them both. They just want you there to talk to them (CNA, Focus Group 11)."

Over half noted the importance of keeping up with residents' medication and, in particular, any medication changes as these can have side-effects that affect resident mood and behaviour. They also discussed the pros and cons of the medications used to aspects of dementia.

Two CA Groups commented on some of the drawbacks:

"Sometimes I think it helps…Sometimes I think it doesn't because we have one gentleman that it puts him in such a listless state. When he has the medicine he's in his room and he just sits there and he's just staring. Won't get up to do anything. His wife lives with him. And she gets very upset when she sees him like that (CA, Focus Group 4)."

One group also commented that facilities were too quick to give medication when more staff time with the resident might solve the problem.

Keeping the resident occupied and not isolating was recommended as was knowing the resident and their family. One group stated that family visits could exacerbate resident behaviour, such as their behaving differently when family members are there and their acting more dependent.

One CNA commented:

"A lot of them get depressed a lot because their family members. Then some will say my family member just stuck me in here, don't come visit me, and I think that's a lot to do with that too. (CNA, Focus Group 10)."

While another commented on families affecting the resident's attitude:

"*Well they get a lot of it from their family members because they tell them I am paying this amount for you to get whatever you want, whatever you need. You are here and the CNAs are to do what you say (CNA, Focus Group 2).*"

Groups disagreed on certain issues. One was whether to give residents choices. Some viewed it as a way to keep them engaged, while other said it increased confusion. There was also not agreement between or within CNA and CA groups as to whether residents CNA control their behaviour.

Other topics were also raised during the interviews. Many noted that those with dementia were at higher risk for falls and incontinence. They also discussed the importance and challenge of identifying residents in pain. They viewed this as critical as pain can lead to combative behaviour or indicate a genuine health problem.

Groups agreed that knowing the resident was key to determining whether they were really in pain. One noted:

"*In the Alzheimer's I don't think they complain about pain much because they can tolerate pain…They don't know if they're in pain…If you really know your residents like you should know them…you know exactly who is in pain and who is not in pain. Now some of them will say they have pain just to get your attention and they're not, but some of them are really in pain (CNA, Focus Group 12).*"

Discussion

The prevalence of dementia was widespread throughout the residential facilities. The data here for NHs mirror that of national statistics, while the ALF values were somewhat higher. The higher percent of residents in ALFs with dementia may reflect that some CAs were working in dementia specific units, although they did not self-identify this way.

Further, dementia is increasingly prevalent in ALFs as many cognitively impaired elders do not meet the requirements for NH care [4]. NH care is also more expensive and many families prefer to delay placement as soon as possible [23].

The direct care workers here were well versed in disease progression and signs of dementia. Formal notification of resident mental status occurred in only half the facilities, while at times it could be found in the residents' chart. Prior research has found inconsistencies in terms of accurately recording dementia diagnoses [24]. This underscores the importance of direct care staff being familiar with the symptoms of dementia given deficits in formal notification.

The characteristics discussed by both CNAs and CAs followed physician diagnostic criteria and symptoms recognized by the Alzheimer's association [2,25]. Their strong knowledge base reflects the extensive job experience of the group with an average of nine years as direct care workers.

They also clearly detailed the specific challenges related to caring for residents with dementia. Execution of quality ADL care was a predominant theme. Communication barriers, problem behaviours and time constraints all hampered these tasks.

Of note is that several interventions have been researched and tested around bathing and eating in long term care residential settings which resulted in quality improvement recommendations [26]. However, their execution involves a substantial time commitment and at times hiring additional staff, both of which are impractical under current staffing levels and reimbursement arrangements [27].

Both CNAs and CAs had recommendations for addressing care challenges and improving quality of care. Prominently discussed was managing their own behaviour and first and foremost avoiding fights. Other themes were the importance of knowing the family, particularly in terms of how they could upset the resident, medication familiarity and safety issues.

Regarding safety, several groups provided graphic descriptions of injuries to them from cognitively impaired residents. A prior study with NH aides reported similar behaviour issues [28]. They also discussed the risks to other residents and to the demented elder, particularly from wandering.

Many initiatives related to wandering have focused on elopement from facilities. Other have focused on facility design and increased staffing. These intra-facility recommendations are unlikely to be implemented due to cost concerns [29].

All direct care staff valued realistic training. Some have argued that training increases job satisfaction and possibly reduces turnover [30]. All groups underscored that education which taught them what dementia is like from the resident's perspective was critical.

Training must also be doable. A recent eLearning course for direct care workers was viewed as positive, but most found it hard to complete given the time commitment involved [31]. Similarly, an initiative by Medicare has run into similar problems and again reflects a lack of direct care worker input [32]. Further peer-to-peer training should be considered given that those with experience often have key insights, particularly in how staff can manage their reactions.

Conclusion

The themes and observations reported here provide valuable insight into quality improvement programs. Clear targets should be: safety, medications, managing ADLs, and recognizing pain.

Staff report that having more time would improve quality and will help with many resident management issues, but until staffing ratios are addressed initiatives need to work within the current requirements. QI programs need to reflect these constraints.

Some initiatives would not be costly. For example, better, standardized communication between facilities and direct care workers, such as passing information about medications would

help. This is critically important in ALFs where nearly 70% of residents are now on medications for dementia [33].

The findings here show that direct care workers have a wealth of information on how to provide quality care and identify targets ripe for QI. Those designing training and QI programs would benefit from incorporating their input.

Limitations

This study has a number of limitations. The direct care workers in this sample were very experienced and drawn from facilities with a strong interest in QI. Workers with less experience may have knowledge deficits and related training needs not identified here.

Also, participants were not randomly selected from facilities, but were chosen by their facility or volunteers. Thus, they may represent higher performing workers with more favorable attitudes towards their job. Workers less satisfied with their employer or direct care in general may have different opinions on care practices and areas for improvement than those reported here.

The sample is comprised of direct care workers in the state of Georgia. CAs and CNAs working in states with different training and certification requirements may have different views than those reported here.

Group facilitators may have influenced participant responses. Also, while focus groups were not held on facility premises and facilitators guaranteed that all conversations would be confidential, concerns about information being passed to their employers may have affected their responses. How these issues affected responses is unknown.

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