
Dementia Care Education

With minimal training and preparation for caregiving roles that are multi-faceted and complex, nursing aides have to learn “on the job” as they care for residents with dementia. A study examined how these front-line workers actually learn to care for these challenging residents.

By JoAnne Henderson

Learning the ropes in dementia care

A learning theory to improve the quality of dementia care provided by front-line workers

In most nursing homes, nursing aides or nursing assistants (NAs) compose the largest group of health care providers. Under a variety of titles (geriatric aide, resident attendant, personal care worker, etc.), NAs provide the lion's share of physical and social care requirements.

Although they frequently care for frail, elderly residents with a multitude of health problems, NAs often have limited previous nursing home experience. Few have been provided formal training for the roles that will be thrust upon them when they enter a nursing home (Robinson, 1993).

Minimal preparation

In Canada, there are few standardized, or provincially certified educational programs for NAs. Although most provinces have programs in NA training, they are of short duration (seldom more than 14 weeks), with the emphasis on dementia care often subordinate to other areas of care.

While many nursing homes attempt to provide the necessary orientation and in-service training, most NAs begin their employment with little preparation or understanding of the job expectations. Regardless, NAs provide 80-90% of direct care to LTC residents - residents with complex physical and mental health problems (Alfredson & Annerstedt, 1994; Stolley, Buckwalter & Harper, 1994; Mutter, 1999).

Challenging behaviours

The major health problem of nursing home residents is dementia.

Estimates are that up to 70% of all LTC residents suffer some degree of dementia, the most common of which is Alzheimer's disease (Swabo, 1991).

As these diseases progress, residents require increasing assistance, even with basic self-care tasks such as bathing and toileting (Gruetzner, 1997). Furthermore, behaviours such as wandering, confusion, depression,

aggressive outbursts, and resistance to care are frequently demonstrated by residents with dementia (Bradley et al., 1995; Gauthier & Pettit, 1997).

Learning to care

Although NAs are the largest group of direct caregivers in nursing homes, their experiences in caring for residents with dementia remain almost virtually undocumented in the literature. In addition, little research has yet focussed on how NAs learn to administer the care required for these vulnerable and often challenging residents.

In light of these realities, a study was undertaken to investigate the experiences of nursing assistants in caring for residents with dementia.

Specifically, this study addressed the following questions:

1. How do NAs learn about dementia?
2. How do NAs learn to respond to the challenging behaviours of dementia?

3. How do they perceive that their care for residents with dementia can be enhanced?

Research findings

The findings of this study resulted in the development of the “*Learning to Care*” theory, a description of nursing assistants’ care responses to the challenging behaviours of nursing home residents with dementia.

Learning to Care is a three-phase, interrelated process that captures the NA’s experiences, and the key factors influencing this process. While the central problem of residents’ behaviours is not solved, the theory provides a manageable lens for examining the way in which NAs learn to care for residents with dementia.

Occurring at different times in the NA’s employment in the nursing home, three phases of the process of *Learning to Care* were identified:

1. learning the ropes
2. gaining experience
3. integrating

Learning the ropes

Learning the ropes begins with the NA’s first day at the facility. During this phase, NAs are introduced to the expected physical care and housekeeping responsibilities incumbent in their new jobs. For many of the participants, this was also an introduction to the variety of challenging behaviours commonly exhibited by residents with dementia.

During this first phase, experienced staff members were assigned as role models or preceptors to assist the NAs in their orientation to the required physical care and housekeeping responsibilities. Frequently, these role models shared strategies for the management of dementia-related challenging behaviours, such as resistance to care, escalating anxiety, sleep disturbances, confusion, aggression, etc.

Gaining experience

The second phase of the process, gaining experience, reflects the period of time when the participants started to work alone. During this phase, participants applied newly acquired knowledge about physical care and housekeeping responsibilities.

In addition, the NAs began to experiment with a range of care-giving strategies, some specific to caring for the residents with dementia. These care-giving strategies were based on observing the more experienced staff, and were developed by “trail and error” according to residents’ responses.

Whereas the beginning of this second phase is marked by working alone for the first time, there is no clearly defined ending to this phase; that is, gaining experience in caring is a continuum of new experiences.

Integrating

Integrating, the third phase of the *Learning to Care* theory, began when NAs start developing or creating care-giving strategies specifically de-

signed to address the particular needs of individual residents.

In this phase, the NA’s caring has become less routine and more specific to the needs of individual residents. NAs incorporated previously acquired knowledge about physical care and care-giving strategies to refine a repertoire of approaches specific to managing challenging behaviours of individual residents with dementia.

In contrast to the previous reliance on observation and trial and error, in the second phase (gaining experience), the NAs’ approach to care was now guided by familiarity with individual residents and their myriad health problems.

As circumstances changed for residents (i.e., progressive neurological deterioration, etc.), or when new residents were admitted, the NAs in this study would return to the first two phases of the process (learning the ropes and gaining experiences) in order to develop novel care-giving strategies to address the needs of these residents.

Although the three-phase process of *Learning to Care* occurred over time, it is not a linear phenomena. Rather, *Learning to Care* is a recursive journey reflecting how NAs shift back and forth among the three phases in order to address the problem of residents’ challenging behaviours.

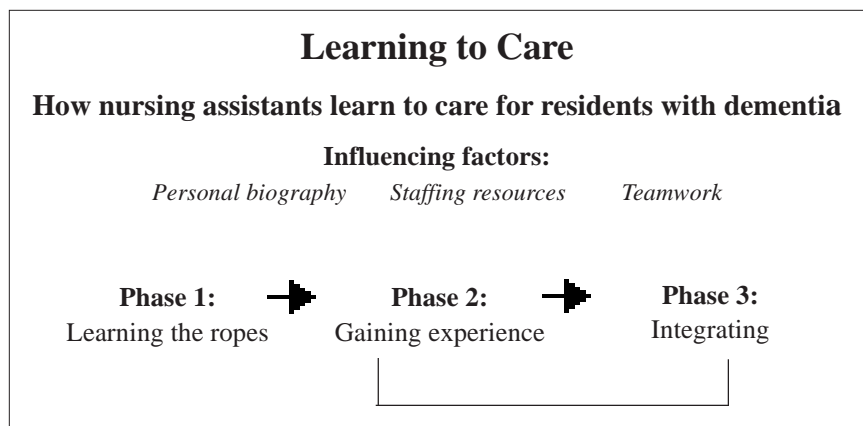
Influencing factors

In addition to this three-phase process, three major factors were identified that influence the process of *Learning to Care*. They have been labelled:

1. personal biography
2. staffing resources
3. teamwork

Personal biography

Personal biography included NAs’ prior life experiences such as caring for a family member or individual with dementia, their previous educa-



tion, and the individual meaning they attached to nursing home care.

Staffing resources

The second factor - staffing resources - included the NAs' changing work load and responsibilities due to changes in staffing levels and the availability of registered nursing staff. Staffing resources also included the NAs' perceptions of availability of the appropriate number of staff to care for residents in the facility.

Teamwork

Finally, the third factor identified, teamwork, included a sense of belonging and opportunities for staff to provide physical assistance and emotional support to other caregivers.

In this study, NAs described teamwork as a supportive and collaborative approach to resident care that promoted the sharing of knowledge and experience. For these NAs, working as a team required the involvement of all nursing home staff. The diagram on the previous page represents the process and the major factors influencing how NAs learn to care for residents with dementia.

Implications

The findings of this study have a number of implications for nursing/care-giving practice.

First, NAs in this study clearly identified the need for greater support from professional caregivers, such as RN/RPN staff and clinical specialists, as well as teamwork facilitated by formal guidelines and regular, multi-disciplinary meetings that include NA involvement.

Most importantly, the findings of this study strongly advocate for NAs to be provided with a more structured and standardized orientation to the nursing home/long-term care environment, and the work and challenges involved. This would facilitate the integrating of care-giving skills with a

knowledge of individual residents and a repertoire of care-giving strategies.

The findings also suggest that educators need to promote geriatric care-aide/nursing assistant courses with a curriculum that includes information about dementia and skills for managing the challenging behaviours associated with dementia.

Educators and facility administrators need to provide regular in-service educational programs to assist in developing the competencies and confidence in care techniques that NAs need in order to provide the quality of care residents with dementia require.

Related questions

Finally, the study should be seen as only a beginning step in understanding the experiences of nursing assistants in caring for residents with dementia.

While the *Learning to Care* theory clearly describes the experiences of this sample, several other questions emerged. For example, this study focussed on a small sample of nursing assistants in a rural setting.

What about NAs in urban areas, or from larger facilities? Or, how do NAs in these facilities, with more professional resources and supports, learn to care for residents with dementia?

Conclusion

The ultimate aim of any nursing theory, such as *Learning to Care*, should be to contribute to making a valued and positive difference in the lives of people needing care.

Given the specific direction for practice and education that emerged from the findings of this study, the theory of *Learning to Care* does have the potential to make a difference in the everyday work experiences of NAs in nursing home facilities.

Most importantly, the findings have the potential to enhance the quality of life for residents with dementia. ■

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This article is an abridged and edited overview of the author's graduate thesis completed at the Faculty of Nursing, University of New Brunswick, Fredericton.

Empathy: a teachable and measurable ability

An essential trait in dementia care

Although empathy has been studied in such health care professionals as physicians and nurses, there has been little evaluation of empathy in front-line staff caring for patients with Alzheimer's disease and other dementia disorders.

Researchers have long been interested in the extent that people are willing or able to imagine themselves in another's situation - to be able to involve themselves at an emotional level and, ultimately, assist in relieving the distress of others. This ability is considered a facet of the construct "empathy," which theorists believe is an essential trait in dementia care.

(Excerpt from *Canadian Nursing Home*, June, 2001)

Empathy is generally regarded as a cluster of characteristics that define the responses of a person to the experiences of others (Johnson, et al., 1983). Most conceptualizations of empathy emphasize the presence of both a "cognitive" and "affective" component (Davis et al., 1987). Some theorists consider "affective" and "cognitive" empathy to be distinct and independent entities. The suggestion is that they be viewed as separate but interrelated. In fact, in certain situations, emotional reactions can be influenced significantly by cognitive states, and vice versa.

Critical role

With this preamble on the definition, it is possible to look at empathy as it relates to professional caregivers as well as para-professionals, i.e., front line workers, care aids, nursing assistants, etc.

Despite the universal acceptance of the critical role empathy plays in patient care, there have been few investigations of empathy as it applies to the health care settings. In fact, in the twenty years ending in 1999, less

than 3% of journal articles addressed levels of empathy in health care professionals. Yet, this is where empathy, however much dissected, is most commonly recognized.

This deficit in empathy studies is occurring in conjunction with an increase in the prevalence of Alzheimer's disease and related disorders - disease phenomena that demand an inordinate amount of empathy.

Enhancing empathy

The questions are posed: Can caregivers with higher empathy levels better meet the care needs of the dementia population than those with lower levels, and can management, through hiring protocols and/or training in empathy enhancement, improve the quality of care provided?

Recent studies show that it is pos-

sible to evaluate the role of empathy in the provision of health care. A news item described in this journal (CNH, 2001) shows that empathy is an important consideration in determining the amount of food eaten by residents with dementia and a trait that is observable: "Although care workers paid attention to the task of feeding a resident, they did not always attend to those aspects that could improve the outcome, such as bantering and conversation and showing empathy for the resident's needs."

Empathy training

In another study over a decade ago (Astrom et al., 1990), the lead author concluded that the incidence of burn-out in caregiving staff in long-term care facilities is "consistently associated with low empathy scores."

Until recently, there have been few investigations of empathy levels in para-professional caregivers, i.e., those individuals who perform 90% of the care duties for those with dementia. One of these investigations was reported in the *American Journal of Alzheimer's Disease* (Gilson and Moyer, 2000). These authors concluded that empathy training may be worthwhile, not only for caregivers at all levels, but for administrators and directors of care as well.

The study also said that there may be a need to enhance empathy levels in male caregivers, especially those who reported lower overall empathy

An historic definition of "empathy" refers to it as a "social intelligence" (Davis et al., 1987). Among other characteristics, "social intelligence" includes sensitivity to the behavioural cues of others and the ability to accurately evaluate the personality traits of others. Both of these abilities in a nursing home environment, to a varying extent, parallel the content of the ideal curriculum for, and attributes of, those who choose to provide direct care (i.e., NAs) to residents with dementia.

scores. Past studies show that empathy levels are different between male and females, with females generally showing a higher degree of empathy when compared to males (Eisenberg and Lennon, 1985). However, as the authors pointed out, the integrity of the study results may not have been preserved due to the small number of males (5%) involved in the sample.

Empathy and care-giving

The study acknowledged that additional research is necessary to discover more about the relationship between empathy levels and the effectiveness of dementia care staff. It mentioned how a study demonstrated that a higher degree of empathy in nurses was associated with a de-

crease in reported patient distress (Olson and Hanchet, 1997).

Since this study did not involve caregivers of dementia patients, the authors concluded that only if empathy was shown to be linked to greater quality of care for dementia patients, could efforts to enhance empathy through hiring protocols and staff training be justified. ■

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Psychiatric symptoms - a step along the way to dementia

Depression, irritability, apathy and other psychiatric symptoms often affect elderly people who have dementia or mild cognitive impairment (MCI), a recent study reports.

"Neuropsychiatric symptoms are common in dementia and MCI," the study's lead author, Dr. Constantine Lyketsos of the Johns Hopkins Hospital in Baltimore, Maryland said.

"This study further confirms the view that psychiatric symptoms are almost universal over the course of the illnesses (i.e., dementia and mild cognitive impairment.)"

But Lyketsos noted that treatment, including, but not limited to, medications, can alleviate psychiatric symptoms. Thus, caregivers "should bring them (the symptoms) to the attention of the doctors in their early stages so that they can be effectively managed before they become disabling."

Psychiatric symptoms

Several studies have shown that 50% to 80% of elderly people with dementia also have some psychiatric symptoms. But there has been little

study of psychiatric symptoms in people who have mild cognitive, or mental, impairment. Mild cognitive impairment is less severe than dementia, but still causes problems with memory and other cognitive abilities.

To gauge the extent of psychiatric symptoms among the elderly with dementia or mild cognitive impairment, Lyketsos and his colleagues reviewed information from about 3,600 people enrolled in a long-term cardiovascular study. The researchers evaluated psychiatric symptoms in 682 participants with dementia or mild cognitive impairment.

Apathy/depression/aggression

In a confirmation of previous research, the study found that 75% of individuals with dementia had experienced at least one psychiatric symptom in the month before the evaluation. More than half reported two or more symptoms and 44% had at least three psychiatric symptoms.

The most common symptoms among participants with dementia

were apathy, depression and agitation/aggression.

The study, reported in the September 25th, 2002, issue of *The Journal of the American Medical Association*, also demonstrated that a substantial percentage of people with mild cognitive impairment (43%) experienced at least one psychiatric symptom. The most common ones were depression, apathy and irritability.

Pre-dementia disorder

According to the researchers, the fact that psychiatric symptoms often accompanied mild cognitive impairment as well, supports the idea that mild cognitive impairment is not a separate condition from dementia, but a step along the way to dementia.

The good news, according to Lyketsos, is that psychiatric symptoms are treatable, especially if detected early. "Treatment not only helps the symptoms but also may delay progression," he said. "By alleviating symptoms, treatment can also benefit caregivers," he added. ■

Resident behaviour patterns common to all personality disorders*

1. Mistrust

Many personality-disordered residents tend to mistrust others; thus, a straightforward, matter-of-fact approach is indicated, as opposed to an overly warm one. Punctuality, honesty, respect and genuineness can add significantly to the formation of trust.

In verbal interactions, avoid interpreting this resident's behaviour because mistrustful people tend to view interpretations as intrusive and controlling. Instead, use open-ended questions designed to assist the person to focus on their behaviour and its consequences. Maintain congruence between verbal and non-verbal behaviours. Incongruent behaviour by a caregiver often causes the resident to become more suspicious.

2. Splitting

The inability to evaluate and then synthesize and accept the imperfections of significant others, both past and present, results instead in dividing all individuals into "all good" or "all bad" categories. The person who is with them at this time tends to be labelled as the "good" staff member or "good" family member. Once out of sight, however, the next person becomes the "good," and whoever has just left is implied to be the "bad." They have distinct classifications and cannot comprehend anything or anyone in a "grey" zone. Once you have done something they dislike, you become a "bad." This can result in staff disagreement as to care plans, etc. This person firmly believes everything he/she says, even though they contradict themselves.

3. Primitive idealization

Magical powers are attributed to certain good staff or the resident physicians. When that person is away or sick, the person becomes so upset and insecure that they will call for reassurance that there is someone there to care for them. One resident, when she discovered her doctor was out of town, called the ambulance and took herself to the emergency department because she knew that there would be a doctor there if she needed help.

4. Projection

The attribution of one's own feelings and experiences onto others. Additionally, personality disordered residents will resort to excessive fault finding, criticism, and confrontation to reduce their own feelings of inadequacy.

5. Passive-aggression

The tendency to turn anger against the self in a provocative manner with the underlying motive of forcing others to comply with their wishes and needs. This tendency is behaviourally expressed through such acts as wrist cutting, non-lethal drug overdoses, and eating disorders like obesity, anorexia and bulimia nervosa.

6. Acting out

Inappropriate reactions to any situation, especially ones where they can deflect their feelings - which they are unable to express onto "taking it out" on others.

7. Narcissism

The tendency to perceive the self as all-powerful and important, and therefore entitled to criticize and belittle others. This individual often gives the impression of being vain and arrogant.

8. Dependency

The expression of incessant, unrealistic wishes, wants and needs, while at the same time, strenuously dependent. This resident has a great fear of abandonment, which probably occurred frequently in the past.

9. No-win relationship style

Since the individual feels that he/she is not a good person, and if you like them, then you must not be good.

10. Denial

When confronted, this resident will deny that the incident occurred, no matter how many witnesses to the contrary. It is not done consciously, but is a desperate attempt to decrease unpleasant feelings. If the issue is too painful, their only method of surviving is to carry on as if the incident did not happen. It is a subconscious reaction and they do not realize that they are denying.

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Different mouse model may see vaccine for Alzheimer's rescheduled for humans in near future

In early 2002, research into a vaccine to prevent Alzheimer's disease suffered a major setback when 17 patients who received the vaccine developed potentially serious brain hemorrhaging. Research into the vaccine, called AN-1792, was suspended by its developer, Elan Corporation and Wyeth-Ayerst Laboratories. New studies, however, may provide a clue about what caused the hemorrhaging - a discovery researchers hope will enable them to figure out how to avoid it when human trials begin again.

Mice that "mimick" AD in humans

In one of the new studies, researchers used the same vaccine that had shown such promise in earlier studies; but this time, they used a different mouse model. The key difference was that the brains of the new mice had a condition that more closely mimicked Alzheimer's in humans than the previous mouse model.

"When these new mice were inoculated, they developed serious brain hemorrhaging," said Dr. Peter Mathews, one of the study's investigators and an assistant professor of psychiatry at New York University School of Medicine. "All of the previous mouse studies have looked incredibly positive, but when we went to humans it was disastrous."

What the new study possesses now, he explained, is an animal model that looks more like the human disease with its severe side effect. The study appeared in the November, 2002 issue of *Science*.

Amyloid-beta plaques

A hallmark of Alzheimer's is peptide clumps called amyloid-beta plaques. They are believed to play a key role in causing Alzheimer's, although it's not known how exactly.

Previous research showed that inoculating mice, who had these amyloid-beta plaques in their brain, jump-started the immune system to produce antibodies. The antibodies cleared the plaques from the brain, suggesting that the vaccine could slow or even prevent dementia. Further research indicated the mice showed improvement in their memory.

"This added a lot of impetus to the idea of using amyloid-beta inoculations as a potential treatment," Mathews said. "Not only did you have a reduction of amyloid-beta plaque, which we think is related to the disease, but we had improved memory, which is clearly related to the disease."

The next step was trials in humans. About 300 people in Europe and the U.S. received the vaccine in the original human trials. About 17 of them developed the potentially dangerous brain inflammation. "It was a real setback," Mathews said. "All of the animal studies had been incredibly success-

ful up until this point. Researchers immediately stopped giving any further doses of the vaccine in humans. However, the patients who received the vaccine are still being observed," he said. Published reports indicate that the vaccine is continuing to work - at least in some patients, and that the brain swelling subsided after the doses were stopped.

A better mouse

In this latest study on mice, researchers tried the vaccine on a different mouse model. Mice used in earlier experiments had amyloid-beta deposits **only** around the neurons of their brains. The new mice not only had amyloid-beta deposits around the neurons, but in the blood vessels in the brain as well - a condition that more closely resembles that of human Alzheimer's patients. "Most Alzheimer's patients have amyloid deposits around the blood vessels, but the mice used in the earlier research did not," Mathews said.

Amyloid deposits can cause a weakening of the blood vessels. When the new mice were inoculated with the vaccine, they developed brain hemorrhaging, he pointed out.

Vaccine side effect

Researchers don't yet know exactly what happened in the brains of the people who developed the hemorrhaging after the vaccine. But hemorrhaging could have very likely been a part of the problem, Mathews said. "Now that we've identified this side effect of the vaccine, we can take a step back, return to animal studies and figure out how to avoid the hemorrhaging."

According to a booklet prepared by the Association of the British Pharmaceutical Industry, there are more than 30 potential Alzheimer's treatments and preventive strategies currently under development at drug companies and academic centers worldwide.

Circumvent the hemorrhaging

For example, researchers at the University of Toronto's Centre for Research in Neurodegenerative Diseases said recently that they have renewed hope that they will be able to circumvent the hemorrhaging that occurs in the new mice models. In a news item in *University of Toronto Magazine* (Vol. 30, No. 2, Winter, 2003), it was reported that researchers there discovered that only a segment of the vaccine produced the beneficial immune response; thus, a smaller portion would be less likely to cause the hemorrhaging in humans.

Most experts agree that immunotherapy, or a vaccine, still holds promise and should not be dismissed as a viable approach to treatment or prevention of AD. ■