In-service Training

Dementia Care: Key Principles

Length: 1 hour

Goals: By the end of this training session, the participant will be able to:

- Describe how the resident benefits from encouragements/assistance of independence.
- Identify the two general approaches to managing challenging behaviors.
- Identify and describe at least four key principles in the management of dementia.
- Identify at least three beneficial environmental modifications.

Suggestions: Consider allowing participants to complete the Discussion Points in small groups or with a partner. If the orientation is for only one or two new employees, experienced staff can be asked to work on the Discussion Points with the new staff members.

Dementia Care: Key Principles

Adapted from the National Institutes of Health (NIH) Pamphlet: "Alzheimer's Disease, Unraveling the Mystery" which can be obtained at www.nih.gov.

In *The 36-Hour Day*, one of the first books on Alzheimer's from the caregiver's perspective, Nancy Mace and Peter Rabins devote several chapters to coping with the symptoms of Alzheimer's disease. "Some people fall when they first get out of bed," they write. "Have the person sit on the edge of the bed for a few minutes before walking." These chapters are about daily routines and problems. "If all of the person's socks will go with all of his slacks, he doesn't have to decide which is right to wear with what... Many families have told us that a bath seat and a hand-held hose greatly reduce the bath time crisis."

When the first edition of this book came out in 1981, it filled a great void. Information on the symptoms of the disease was sparse and guidance on managing them even sketchier. Throughout the 1980's, other publications appeared, filled with informal observations about symptoms and coping strategies.

Toward the end of the decade, more and more formal research began to focus on this aspect of Alzheimer's disease. In contrast to the biological research described earlier, the low-tech, behavioral approach centers as much on family members and *caregivers* as on the patients themselves. The rationale is that if the people who care for Alzheimer's patients know how to cope with symptoms of the disease, they can reduce the degree of disability associated with it.

Current studies are looking at two kinds of caregiving strategies: those that help the patient maintain independence in daily activities as long as possible and those that help prevent disturbing behaviors.

Independence

Dressing, preparing simple meals, performing other household tasks: These are all things that many Alzheimer's patients can still do in the earlier stages of the disease. "If we go out," said Letty Tennis in her journal, "I still can fix my face and hair perfectly but I forget basic steps and go by a little piece of paper like do eyes, cheeks, lips, etc.... I never cook when alone...but I still can microwave."

Maintaining independence has obvious advantages: The longer the patient can function independently, the better his or her quality of life and self esteem. Strategies that increase or maintain independence as long as possible also lower the level of stress for the spouse, child, or other caregiver.

Researchers are experimenting with several methods to slow the loss of independence. Some are looking for ways to improve cognitive functions. For instance, one research team has used mental stimulation exercises for 1 hour each day in an attempt to improve cognitive abilities. So far, the Alzheimer's patients who do these exercises show improvement in comparison with a control group. Moreover, the caregivers in the group who did the exercises reported lower stress levels. Researchers are now testing mental exercises in group settings outside the home.

Other studies are testing ways to improve patients' functional abilities. This term encompasses the ability to carry out the so-called *activities of daily living* (ADLs), such as dressing and eating, as well as the more complex instrumental activities of daily living (IADLs). The latter include tasks like shopping and cooking.

Some findings show promise. Techniques that have been successful in small studies of getting dressed include having the caregiver demonstrate what to do, so that the patient can mimic the action (the technical term is "modeling"). Another technique is laying out clothes in the order that they should be put on ("stimulus control"). Still another is "prompting." Verbal prompts are statements like, "Pick up the shirt. Put your arm in the sleeve." Physical prompts are when the caregiver uses touch to show the patient which arm to use.

Researchers are now extending these strategies to other activities, such as bathing and feeding. One of the most intriguing results of such studies is the effect that the strategies have had on other aspects of Alzheimer's disease. Improved functioning seems to go along with a significant improvement in the behavioral problems that afflict Alzheimer's patients and families.

Disturbing Behaviors.

In one of his journal entries, Cary Henderson commented: "I think this disease does make us kind of irrational--sometimes very irrational--and sometimes it's out of fear and sometimes it's being left out of things."

As Alzheimer's disease makes inroads into memory and mental skills, it also begins to alter emotions and behavior. An estimated 70 to 90 percent of Alzheimer's patients eventually develop behavioral symptoms. One of the most common is agitation, which Letty Tennis describes: "It's a feeling like no other--like your engine is racing 100 mph and you can't go anywhere.... I'm getting cross at people and I hate that. When my psychologist kept asking me questions--the same ones over and over, I got so impatient inside that I had a strange impulse to throw my purse on the floor or better yet to bite him and say NO MORE!"

In addition to agitation, Alzheimer's patients often experience feelings of anger, frustration, and depression. The disease can also lead to wandering, pacing, and screaming. Behavioral symptoms may become worse in the evening, a phenomenon called *sundowning*, or during certain daily routines, especially bathing. These symptoms of the disease and their effects on the family are thought to be one of the most common reasons that Alzheimer's patients are institutionalized.

Medications

Drugs are one way to approach the behavioral symptoms of Alzheimer's disease. Most often prescribed are anti-psychotics or antidepressants, which were developed for use in psychiatry. They can have a tranquilizing effect, although physicians and caregivers report varying results with these drugs. Few scientific studies have tested their effectiveness specifically in Alzheimer's disease.

One area of special interest is the effect of antidepressants on cognitive function. Many antidepressants suppress activity in the neurons that use acetylcholine. These are the same neurons affected by Alzheimer's disease, so suppressed activity in these neurons might make the cognitive symptoms, such as loss of memory, even worse. Some studies show this may be true.

On the other hand, there is evidence that reducing depression may improve functional ability in people with Alzheimer's disease. In one study, for example, those patients who were more depressed were less able to carry out the activities of daily living than patients who were less depressed. The effects of depression on functioning appeared to be over and above the effects of cognitive impairment. This finding interests researchers because it raises the possibility that treating depression may be one way to improve functional abilities.

Behavior management

The other approach to the behavioral side of Alzheimer's is itself behavioral. That is, it relies on behavior management techniques rather than drugs. Some behavior management techniques aim to influence the entire spectrum of disturbing behaviors. One study, for instance, is looking at the effects of bright lights and music on all behavioral symptoms. Another is testing a daily schedule of planned activities for patients and caregivers on the hypothesis that regular routines can alleviate many disturbing behaviors as well as reduce caregiver stress.

Other behavior management techniques have specific targets. Aggressiveness and agitation commonly afflict patients during bathing, for instance, so researchers are trying to pinpoint the precise circumstances or events that trigger the problem. They then will test methods of avoiding those triggers or alleviating the patient's distress in other ways. Wandering and pacing are also common among Alzheimer's patients. One hypothesis suggests that if pacing and wandering can be accommodated in some way, both patients and caregivers will benefit. To test this idea, one researcher has arranged for Alzheimer's patients in a nursing home to have access to an outdoor sheltered park for pacing. In addition, the researchers have had stimulating patterns painted on the floors. The study will compare the effects of this approach to the effects of drugs and physical restraints, the more traditional ways to manage pacing and wandering.

Screaming, also common among Alzheimer's patients, may be affected by changes in the environment as well. Several researchers are testing the effects of music. One is experimenting with videotapes of the patient's relatives and direct social interaction, to see if they have an effect on screaming.

Studies of behavior management techniques fall into two groups. Many are still small descriptive studies. That is, their aims are to establish a base of knowledge about the disturbing behaviors, such as how prevalent they are and what circumstances trigger them.

Other studies are clinical trials of strategies that seem most promising. One current trial is comparing the effects of non-drug behavior management strategies to the effects of two different medications, haloperidol and trazodone, in treating disturbing behaviors.

Caregiving

"You don't know when it's going to end or what to expect."
"Your friends...will say we think of you, or we'll visit, but they never do, because they don't know how to act around Alzheimer's."
"I must have looked at 30 different homes."

These quotes, culled from support groups and personal conversations, express a few of the special problems that confront the wives, husbands, children, and other family members who take care of Alzheimer's patients.

Formal research on caregiving, begun in the early 1980's, is still young. The early studies documented that caregiving has a severe impact on both the physical and mental health of the caregiver. Fatigue, insomnia, and other physical symptoms are frequent. Cardiovascular risk factors, such as high blood pressure, may be affected. Studies also have linked the high levels of stress in caregivers with depression, a sense of isolation, and strained relationships with other family members.

What can be done to reduce the burden?

This is a critical research question. Scientists are testing various methods (known in the language of research as interventions) to help caregivers. These fall into three broad categories.

Emotional support
One major hypothesis is that social support can help reduce stress and other caregiving problems. Support groups, individual counseling, and family counseling all fall into this category, and they are being studied in various ways. For example, one study is comparing two different forms of social support--support groups and home visits from professionals--to see if one is more effective than the other in boosting caregiver well-being and reducing the sense of burden.

To date, studies have generally shown a high level of satisfaction with support groups, although it is not clear whether they also help decrease caregivers' sense of burden. Individual counseling has alleviated specific problems such as depression.

Services
Help from community groups or professionals is another promising way to ease the difficulties facing caregivers. Probably the most common service, and the most studied so

far, is *respite care*. This is the broad term for a variety of situations in which someone else cares for the patient for a period of time, giving the principal family caregiver some temporary relief. Respite services are offered in the home, in day care facilities, and even in institutions where patients stay a limited time, usually a week or two. So far studies of respite care show a very modest benefit, and current research is looking for ways to increase its impact.

Knowledge and skills training

Another active hypothesis is that Alzheimer's caregivers will benefit by learning more about the disease, including the resources available to them and specific skills for coping with its symptoms. Research projects, for instance, have trained caregivers in behavior management techniques and other ways to resolve day-to-day problems.

The outcomes of many of these studies are positive, in that caregiver behavior and sometimes patient behavior is changed. In some cases, these studies have also demonstrated improvements in caregiver stress, anxiety, and depression. On the other hand, some of these studies show that decreased stress does not necessarily translate into a reduced sense of burden.

A fourth category of interventions combines all three of these approaches. Studies of such comprehensive efforts suggest that the more components they have, the better the chance that they will meet the needs of caregivers. However, questions remain about the cost effectiveness of comprehensive interventions and about the relative benefits of their individual components.

Other approaches

In the attempt to develop better interventions, researchers are now trying to find and sort out the many factors that determine caregiver stress. For instance, one study is looking at caregiver personality, the degree of care needed, and resources available to the caregiver. The study's goal is to see how these factors interact to influence the caregiver's sense of burden.

Studies are also exploring when and how Alzheimer's caregivers use formal services--adult day care or home health aides, for instance. So far, the findings suggest that most caregivers delay getting formal services until their situations are extremely stressful.

Keys Principles in the Management of Dementia

The management of dementia has to be multidisciplinary, with many professionals involved and many approaches considered. The key principles are outlined as follows:

Discuss avoiding medications that have nervous system side effects with the physician.

Many commonly prescribed medications can have nervous system side effects, including dizziness, sedation, confusion, and agitation. For the resident with dementia these side effects, in the presence of the symptoms of dementia, can be devastating.

Assess the environment and consider alterations.

Simple changes in the environment, including labeling common items, reducing background noise, and providing colorful stimulation can have significant benefits on the resident's symptoms. Reducing agitation, and possibly confusion.

1. Encourage a homelike setting: familiar furniture, comforters, pictures, and decorations.
2. Display resident's artwork or pictures related to the resident's favorite hobby.
3. Eliminate background noise: play soft music during meals and ADLs.
4. Chairs should be easy to get in and out of, and tables at the correct height.
5. Drawers and closets should open easily.
6. Avoid clutter which can increase confusion and agitation: from excessive decorations, or general clutter around the facility.
7. Place a photo of the resident on her door to make navigating the hallways and finding her room easier: older photos tend to be more familiar to the resident.
8. Place signs on bathroom doors: a picture or a toilet, the word bathroom, etc.
9. Shadow and glare can be extremely problematic: use soft, but sufficient lighting.
10. Keep common areas and hallways easy to navigate: adequate lighting, good spacing between furniture, color contrast between floors and walls, adequate handrails.

Encourage and provide opportunities for the resident to remain physically and mentally active.

Activities in the facility should stimulate both the physical and mental functioning of the resident. Large motor and fine motor skills should be considered. Stretching, yoga, walks, and playing ball can all be extremely beneficial and adaptable. Additionally, art and crafts, writing letters to family, and working in window box gardens can stimulate fine motor skills.

Mentally stimulate the resident with appropriate puzzles and board games. Conversation, current events discussion, and reminiscing are also very effective with the dementia resident.

Identify and manage complications.

- Problem behaviors, such as wandering
- Depression.
- Agitation and aggressiveness
- Delusions and hallucinations
- Incontinence
- Difficulty with swallowing (dysphagia)

Provide ongoing care and assistance.

- Provide necessary assistance with ADLs.
- Encourage the resident to remain an active participant in her care.
- Consult the physician for treatment of medical conditions.

Dementia is certainly a devastating problem, for resident, family, and caregiver. Through carefully planned yet often simple management techniques, the impact on the resident can be lessened. The keys are patience, understanding, and support from caregivers, physicians, and family.

Comprehension exercise

ENVIRONMENTAL ALTERATIONS

Few things have as significant an impact on the client with dementia as the environment. Walk through the facility in two or three groups looking for environmental alterations that have been or could be made to benefit the client with dementia. After your "tours" return to the classroom and discuss what you found. Discuss steps that could be taken to make additional alterations you identified.

Environmental alterations already made in the facility.

Additional environmental alterations that could be made in the facility.

Quiz

KEY PRINCIPLES IN THE MANAGEMENT OF DEMENTIA

True and False

1. T F The management of dementia is primarily from a medical approach, through medications, surgeries, etc.

2. T F Placing a picture of the client on her door is an example of an environmental alteration.

3. T F Medication side effects can cause a decline in the client's cognitive function, beyond that caused by the dementia.

4. T F Problem behaviors and depression must be monitored for and managed by the facility staff and supervisors.

5. T F The client with dementia will perform most ADLs independently.

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Dementia Care: Key Principles

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Orientation/In-Service Sign-in Sheet

Orientation/In-Service Topic/Title:

Date:

Location:

Instructor/Title/Signature:

Notes:

Name (print)	Signature

Certificate of Completion

THIS IS TO CERTIFY THAT

HAS COMPLETED THE FOLLOWING IN-SERVICE TRAINING

Administrator/Instructor

Date