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Habilitation Therapy in Dementia Care

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Case Study

Habilitation Therapy in Dementia Care

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Educational Objectives

1. To describe the goal of Habilitation Therapy and how it differs from other methods of dementia care, including rehabilitation.
2. To identify areas or domains in which we have opportunities to bring about and sustain positive emotions.
3. To discuss four communication strategies to use with mid- to later-stage Alzheimer's patients.

Background

Until recently, the life of the person with Alzheimer's disease was defined as revolving entirely around inevitable loss, for Alzheimer's disease has been seen as a disease for which there is no cure and no treatment. In consequence, we have devoted all of our resources to biomedical research in order to find the "magic pill."

Although a cure is nowhere in sight, the paradigm holds enormous power among professionals and the public at large. A contrasting view sees Alzheimer's disease and related disorders as disabilities, albeit caused by progressive and fatal neurological illness. In this view, individuals respond to their disease according to how supportive their environments are. Here, the emphasis is on active treatment of the symptoms of the dementia through a careful focus on those capacities that remain, particularly the person's psychological capacity. Developing a better understanding of the psychology of dementia, i.e., how a person thinks, feels, communicates, compensates, and responds to change, to emotion, to love, may bring some of the biggest breakthroughs in treatment. This new paradigm, which my colleague Joanne Koenig-Coste and I introduced in 1996 as *habilitation* (Raia & Koenig-Coste, 1996), is more a disposition or a way of thinking than a complete therapeutic model.

The aim of "habilitation therapy" is not to restore people with a dementia such as Alzheimer's disease to what they once were (i.e., rehabili-

tation), but to maximize their functional independence and morale. This approach also allows minimizing or eliminating many difficult symptoms of the dementia, in spite of the person's progressive physical, cognitive, and emotional illnesses. The primary learning task becomes how to value what is still there and not dwell on functions the person has lost. To borrow from the philosopher Erich Fromm (1976), family and professional caregivers need to emphasize "being" rather than "having." This model is no cure. But it is a systematic behavioral method of treating symptoms that can benefit both the person with Alzheimer's disease and the caregiver.

Habilitation Theory in Practice

The goal of habilitation therapy is deceptively simple: to bring about a positive emotion and to maintain that emotional state over the course of the day. Clinically, however, it presents a challenge. If cognitive capacities involving memory, logic, reason, decision making, judgment, language, attention, perception, and motor control all are being gradually lost to the disease, what remains?

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What cognitive capacity can we use as a channel into the brain? The answer: the capacities to feel and exhibit emotions, to perceive emotions in others, and to respond to emotion persist far into the disease process. Habilitation therapy can be defined as a proactive behavioral/milieu therapy activated within five “domains:” critical areas in which positive emotions can be created and maintained. Stated another way, a domain is an opportunity to bring about a positive emotion or, at least, to not cause a negative one.

The Physical Domain

Even a once-familiar environment can become frightening and confusing to someone with Alzheimer's disease. Within the physical domain, the habilitation therapy model attempts to reduce the potential for fear and disorientation by “directing” cognition, often without the person’s awareness. In this way, the manipulated environment becomes a prosthetic for the brain, enabling the person to function with limited frustration.

A well-designed prosthetic environment, like all the other domains in this model, has as a goal to bring about a positive emotion and to maintain that emotion.

Case Study

A 73-year old woman with Alzheimer's disease, living at home with her husband, was having difficulty dressing herself in the morning. He would take her to her enormous walk-in closet and say it was time to get dressed. When he would return 20 minutes later, she was

still standing in the closet in her nightgown. Alzheimer's patients have problems making decisions, so the environment had to be altered to reduce the number of choices. I instructed the husband to remove all but two or three outfits from the closet and suggested that he say something like: “We have two very pretty outfits here, a blue one and a red one. I like the blue one because it matches your eyes. Which one would you like to wear today?” Once we limited the number of choices, she was able to get dressed on her own. With her environment structured so that she can use her remaining skills, chances are that she will hold on to these skills longer. It also serves to bring about a positive emotion because she feels more independent.

Perhaps the single most important adaptation to an environment is enhanced lighting. By increasing artificial light from approximately 30-foot-candle power (typical lighting in a home) to 60- to 70-foot-candle power and controlling the glare and shadows from outside ambient light, we can improve independence, reduce late afternoon and early evening agitation, promote better sleep patterns, and stabilize mood.

The Social Domain

Structured activities are the engine that drives the social domain. Understandably, people with Alzheimer's disease who spend significant amounts of time doing nothing experience more psychiatric symptoms, such as depression, anxiety, paranoia, delusions, and hallucinations, than people who are occupied by a meaningful activity.

By developing a failure-free activities plan, we can avoid cognitive skill areas that have been lost. This plan may require that the person’s cognitive strengths and weaknesses be assessed through a battery of neuropsychological tests. A cautionary note: For some patients, these tests can cause frustration and bring about negative emotions. In these instances, our knowledge of the patient and observation of his or her skill level are better indicators of how to design failure-free activities.

In the social domain, time is filled with opportunities for reminiscence (e.g., cooking classes, word games, and holiday reflections), for fun (dancing, sing-a-longs), and for creativity (herb gardening, jigsaw puzzles, and art projects). However, these activities are not “time fillers” but carefully and individually selected cognitive enhancers that maintain healthy neural connections and promote branching or arborization of neurons. Branching of neuronal axons allows an electrical impulse in the brain to bypass damaged areas of the brain and make connections with healthy cells. So, failure-free activities help individuals hold on to their capacities longer and maintain positive emotions. Another benefit of activities, especially musical activities, is that they very quickly change emotions. To address his wife’s “sundowning” behavior (late-day confusion), one caregiver began ballroom dancing with her late every afternoon. She enjoys it and does not experience sundowning, plus they are able to relive some previously inaccessible personal emotions of their youth. Thus, activities can be used prophylactically to avoid anticipated

swings in mood or increased confusion. An activity cannot be introduced once the person is already agitated.

Case Study

An all-dementia program at one facility focuses on education as a formal activity. The staff created week-long educational modules on various adult topics. For one week, residents attend an hour and a half long morning discussion on a set topic, say Italy, where they would study the history, culture, food, art, geography and political system. In the afternoon, they would meet again for an hour and a half and do something related to what they discussed that morning. They might listen to an opera, make a food, go to an art museum, etc. The intention is not on the retention of information, but rather, on the joy of being in a learning environment with peers. The staff developed more than 30 different week-long modules.

The Communication Domain

Nowhere in the habilitation model is the process of eliciting positive emotions more critical than in the communication domain. In our highly verbal world, expressive and receptive language deficits are catastrophic losses for someone with Alzheimer's disease. In the communication domain, habilitation therapy calls for increased use of body language, encouraging the use of gestures, demonstrations, signs, and pictures. Here are summaries of four strategies, with a fuller discussion available in Raia (1999).

The first strategy of habilitative

communication is that one can never change behavior with words, but only by changing what one does, the approach to the patient, or the environment. Because the patient has no short-term memory and limited capacity to learn, we cannot tell the patient to do something or not to do something and expect him or her to remember it the next time.

The second strategy is never to use the word no. If the patient wakes up at 4:00 a.m. and wants to take a walk outside in a rainstorm, one should say, "Sure, let's do it." If one says no, muscles tense up, tone of voice changes, and the patient sees the caregiver as limiting his or her independence. Even if the patient is given the most logical, eloquent argument why he or she should not go outside, there is nothing in his or her brain that can appreciate the reasoning. Rather than logic, one should use distraction. Two techniques, "refocusing" and "redirecting," help distract the patient long enough so that his or her faulty memory will work to the caregiver's advantage. For example, one might say, "Sure, let's go walk in the rainstorm, but before we go, I need to have a cup of tea and a sandwich. My favorite kind of sandwich is turkey. What's yours?" The caregiver is refocusing the person's attention. He or she then might go on to say, "Help me make the sandwich." Such dialogue redirects behavior.

The third strategy, perhaps the hardest to learn and apply, is that one never brings a midstage patient back to our sense of reality; rather, the caregiver must go to where the patient is. Reality orientation as a

therapeutic technique works just fine for cognitively intact elders, but it is not at all useful for mid-stage confused patients with Alzheimer's disease.

A fourth communication strategy emphasizes our roles in reducing fear for the patients and acknowledging underlying emotions. As they decline and lose capacities, part of what is also lost is the ability to articulate their fears and cope with them. Essentially, what is lost is the person's ability to self-soothe if fears become overwhelming. The focus of our communications is to make the person feel loved and safe.

Habilitation therapy underscores listening techniques related to emotions, directing us to listen not so much to the often misused words and muddled sentences, but to the driving emotion behind them. For example, if the person is experiencing symptoms of suspiciousness and accuses the caregiver of taking her pocketbook, the caregiver can say something like, "I know how you feel. When I lose my pocketbook [or wallet] I feel panicky. Let me help you find it." You have acknowledged the validity of the patient's emotion and once this offer of assistance is communicated, the outcome is likely to be a change in the person's emotional state.

Case Study

Evelyn, a 91-year-old widow with dementia, becomes increasingly confused in the late afternoon and early evening, a condition referred to as "sundowning." During this period, Evelyn might approach a

caregiver and say that she just saw her mother. Using “reality orientation,” the caregiver tells Evelyn that her mother is dead and that she did not really see her. This propels Evelyn into mourning because it is the first time she has heard that her mother has died. The tragedy here is that within a matter of seconds Evelyn forgets that she was told her mother is dead, but she is left with the emotion of profound sadness with no context for it, and no ability to control the emotion. Within habilitation therapy, rather than tell the patient that her mother is dead, we would say, “Tell me about your mother. I hear that she is a wonderful person.” Or, if this happens frequently and predictably, the caregiver could have a picture of the patient and her mother taken many years earlier and use the picture to create a story, which may or may not be true, to bring about a positive emotion.

The Functional Domain

All too frequently in Alzheimer's care we note an inability to perform routine tasks sooner than would be expected from the trajectory of the disease. Dysfunction caused by the person's emotional reaction to the disease (e.g., depression) or to physical or care factors in the environment is said to be an “excess disability.”

Excess disabilities with environmental causes can be avoided by creating supports that encourage independence in the person's activities of daily living: eating, walking, toileting, dressing, grooming, and bathing. As in the activity domain, previous routines become the cornerstones here, as caregivers strug-

gle to keep one step ahead of dependence. To preserve the person's sense of worth we need to ask, if she fails at more complicated chores, can she instead help by shredding lettuce or setting the table?

Caregivers also can change the task to fit the person and prioritize which activities for daily living (or parts of an activity) are important and which are not. Bathing, for example, may be the most difficult activity asked of the person. One should begin by spending at least five minutes just talking and building rapport. This is what I call the “spend five and save 20” rule. Proposing an activity as a question (“Would you like to take a bath?”) too often leads to a resounding “no.” Assist the person with verbal cues, using a technique called “chunking,” which involves a series of short, simple, calmly stated commands, such as “come with me,” “unbutton your shirt,” “take out your arm.” Schedule bathing when the person is in the best frame of mind, most alert, and cooperative. If necessary, provide hands-on assistance, mindful not to let water pour over the person's face and eyes, which can be frightening. Wash the hair and the face at a different time. Showering for a patient with Alzheimer's disease is best done from the feet up, stopping at the neck, rather than working from the head down.

Case Study

Tom, a 53-year-old patient with Alzheimer's disease, had great difficulty with his morning shower, being combative and behaving poorly afterward. Under habilita-

tion therapy it is imperative to intervene and prevent the development of the negative emotion. The first step is triage. If showering is so difficult for him, how many times a week are we willing to risk starting off the day with a negative emotion? Talking with this man's family revealed that there were four things that calmed him: backrubs, blue sports cars, women in short skirts, and the music of the Beach Boys. We developed an intervention that employed these calming agents. To begin with, only one nursing assistant was involved with assisting with this man's shower rather than three aides involved previously. The aide would come into the man's room and just chat with him for a few minutes, the “spend five to save 20 rule.” She then gave the man a backrub to create a relaxed mood. Once he was relaxed, she simply said, “Come with me,” and led him down the hall to the shower. On the walls between the “young” patient's room and the shower we had taped pictures of blue sports cars and tasteful pictures of women in short skirts to distract him and avoid any anticipatory anxiety. In the shower room, the music of the Beach Boys was playing; the room was warm and well illuminated. While singing with the young man, the aide undressed him, giving him a bathrobe to avoid modesty problems. Using a handheld shower nozzle, the aide started washing at the man's feet and quickly moved up the body, stopping at the neck. The actual washing took less than three minutes.

The Behavioral Domain

To manage problematic (i.e., reac-

tive) behaviors successfully, the habilitation therapy model requires that caregivers adopt a dementia-centered perspective. This accepts that we cannot change the person's behavior directly, but only indirectly by changing either our approach technique or the person's physical environment.

Difficult behaviors in people with Alzheimer's disease are most often defensive in nature, such as compensation for the confoundedness or fear of an increasingly unfamiliar world. Behavior, in this sense, is a form of communication directed to us. Sometimes these events are obvious because they are external, we can see them, and sometimes triggers are more difficult to see because they are internal, caused by delusions, hallucinations, paranoia, or misunderstood events and motives. Internal triggers can be more physical in nature, for example, pain, hunger, dehydration, constipation, infections, fever, sleep deprivation, etc. Caregivers must assess several possible causes for each challenging behavior.

Case Study

Will, who has Alzheimer's disease and lives in a nursing home, would on occasion calmly get up from his chair, walk across the room, and hit another resident. By keeping a log, we began to see that he would only hit someone if he was in the activities room, but not every time he was in that room. Later, we saw that he would only hit people on sunny days, but not on every sunny day on which he was in the activities room. Then, we saw that he only hit people on sunny days if he was sitting on one side of the room.

With the log we were able eventually to determine that he would hit people if he sat in the activities room and the sun was shining in his eyes. The intervention was simply to make sure that the blinds were closed on sunny days if this particular man was in the activities room. Thus, with patience and careful analysis of the situation we were able to avoid the use of a psychoactive medication. Of course, it may be dangerous to allow repeated episodes of assaults to occur in order to gather data to determine the cause of the triggering behavior.

Conclusion

Through its multiple and interconnected domains, habilitation seeks to create a proactive therapeutic milieu for understanding the needs of people with Alzheimer's disease. It differs from rehabilitation, which seeks to restore external function, by its emphasis on the internal: emotion. Habilitation is as much a positive attitude about Alzheimer's disease and related disorders as it is a therapeutic method.

Study Questions

1. How would you use Habilitation Therapy techniques to address restless behavior in a midstage Alzheimer's patient in the late afternoon?
2. Using your kitchen at home as an example to work from, how could you modify it to be more of a prosthetic supportive environment for someone with Alzheimer's disease?
3. How would you assist someone with Alzheimer's disease in brushing her teeth? Give the actual directions you would use and the way you would introduce the task

using Habilitation Therapy methods.

4. Why does Habilitation Therapy focus so much on emotions?

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