

Developing Personally Relevant Goals for People with Mild Dementia

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ABSTRACT

Many speech-language pathologists work in the skilled nursing facility setting and frequently treat patients in subacute rehabilitation who are experiencing mild cognitive deficits as a result of dementia. Treatment of these individuals needs to be carefully differentiated from rehabilitative treatment of a stroke or traumatic brain injury. A “habilitation” approach should be considered, focusing on an individual’s preserved strengths and developing patient-centered goals that focus upon the integration of personally relevant stimuli into the care plan. Environmental modification, the use of visual memory aids, counseling, and ongoing family education are also essential components of this approach. This case study is a thorough example of how the habilitation approach can be used to provide intervention for a person with mild dementia. The case study will explain indication for treatment, assessment, goal selection, and research to support the treatment plan.

KEYWORDS: Evidence-based practice (EBP), dementia, habilitation, caregiver education, skilled nursing, long-term care

Learning Outcomes: As a result of this activity, the reader will be able to (1) develop personally relevant goals, and (2) support the need for a habilitation approach in the mild stages of dementia, including use of visual memory aids, spaced retrieval training, errorless learning, counseling, and caregiver education.

By the year 2025, an estimated 7.1 million Americans over the age of 65 will suffer from Alzheimer’s disease.¹ This statistic excludes other types of dementias, including young-

onset dementias. Speech-language pathologists (SLPs), regardless of setting, will encounter adults with neurodegenerative diseases on a regular basis. SLPs are uniquely equipped to

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work with individuals and families coping with these devastating diagnoses, with an expertise in the neurophysiology of the diseases, but more importantly having the ability to counsel and educate families about the diagnosis while creating a unique plan of care. A dementia diagnosis often results in social isolation, a loss of dignity and independence, and decreased participation in meaningful activities. Individuals and families affected by these diagnoses are in desperate need of interventions that are personalized and that have the ability to be generalized to everyday situations. SLPs are traditionally trained to use the “rehabilitation” approach, which focuses upon fixing what was “broken” and identifying weaknesses to improve. A paradigm shift will need to take place, moving away from constantly testing these individuals to identify weaknesses and instead shifting the focus to a person-centered habilitation approach.² Taking advantage of the individual’s strengths, developing personalized compensatory strategies and memory aids, modifying the environment, training family members and caregivers, and most importantly, integrating the individual’s interests and passions into the plan of care are all essential components of this approach. Embracing the habilitation approach takes perseverance, creativity, and the willingness to toss aside the cognitive workbooks and brain games; it involves looking beyond “staging” the level of dementia and instead discovering the person beneath. This article and its partnered article will illustrate the habilitation approach in action through the use of case studies in the skilled nursing setting, the first focusing upon a functional approach in the mild to moderate stages, and the second upon using the same approach in the moderate to severe stages.

Note: These cases were written by the authors for educational purposes and are not based upon actual patients.

INTRODUCTION

SLPs are often confronted with referrals for patients involved in a short-term rehabilitation stay in the subacute setting, as a result of a fall or deconditioning, with many patients presenting with a concomitant cognitive decline or demen-

tia diagnosis. These short-term stays present SLPs with a unique opportunity to provide the patient and family members with education and counseling regarding their diagnosis, in addition to developing a plan of care that targets specific strategies that may be implemented in the home environment upon discharge. The following case study illustrates one example of use of the habilitation approach to focus upon personally relevant goals for an individual in the mild stages of Alzheimer’s disease in the skilled nursing subacute setting.

BACKGROUND/HISTORY

Nancy was a 75-year-old retired nurse practitioner who lived at home with her husband Robert in the suburbs of Chicago. They had been enjoying retirement for the past 10 years, traveling abroad and becoming involved in volunteer opportunities around their community. Nancy also enjoyed cooking and gardening. They had one daughter, Amy, who lived nearby, and two young grandchildren. Robert, a former internist, volunteered at a walk-in clinic 1 day a week.

Robert first noticed some changes in Nancy 2 years previously. Always an articulate person, she began struggling with thinking of the word she wanted to say and frequently used phrases such as, “You know what I mean” and the word *thing* in conversations. Robert also noticed that Nancy repeated herself during conversations and had trouble recalling the dates and times of her appointments and volunteer events. She began to misplace important items around the home and had trouble multitasking while cooking more complicated recipes. Although Nancy admitted to having some difficulty with her word finding, she brushed aside Robert’s concerns regarding her memory difficulties, saying, “Everyone forgets things as they get older.”

Amy finally persuaded Nancy to see a neurologist at a memory clinic in Chicago. After a magnetic resonance imaging, spinal tap, and neuropsychological testing, Nancy was diagnosed with dementia of the Alzheimer’s type. Shortly after her diagnosis, Nancy was admitted to the hospital after a fall while walking downtown, which resulted in a pelvic fracture. She was discharged from the hospital to a skilled nursing

facility for rehabilitation. A speech-language pathology consult was ordered after it was noted that patient suffered from memory loss due to Alzheimer's disease.

ASSESSMENT

A chart review revealed little information, other than Nancy's diagnosis of Alzheimer's disease and hospitalization records. The SLP collaborated with both physical therapy and occupational therapy before the evaluation as they had already completed their assessment. Both indicated that although Nancy exhibited some short-term memory loss and anxiety about the situation, she did not seem to have trouble following directions or sequencing the steps for transfers during their sessions. The SLP spent the first few minutes of the assessment casually conversing with Nancy and learned that she felt overwhelmed by all of the different health care professionals who had visited her that morning. The SLP immediately made Nancy a visual memory aid on brightly colored paper, listing the name of the facility, why Nancy is there, and all of the health care professionals involved in her care. The visual memory aid also included reminders about use of the call light to call her nurse and a note regarding her pelvic fracture precautions. The Bourgeois Oral Reading Measure was used to determine appropriate font size.³ The memory aid was placed in a plastic page protector and set on Nancy's bedside table.

The SLP then initiated structured conversation targeting items in the Functional Goals Screening Protocol: Community Clients with Dementia, including family, friends, preferences, former occupation, and her hobbies.⁴ Throughout the evaluation, the SLP noted that Nancy demonstrated little awareness of her memory deficits; however, she did acknowledge frustrations regarding her frequent word retrieval difficulties. Nancy also admitted that she worried about the future and maintaining her independence. Her ability to cook, garden, and continue her volunteer work was extremely important to her.

During this conversation, it was noted that Nancy's long-term memory was excellent; however, Nancy had difficulty recalling the names of

her grandchildren, the names of flowers she plants in her garden, and places she has traveled with her husband. Nancy also told the same story regarding her history as a nurse practitioner three times during the evaluation, and frequently asked, "What did you say your name was?" To further assess the severity of Nancy's short-term episodic memory loss and to provide a standardized test score in the documentation, the SLP administered the story retell subtest of the Arizona Battery for Communication Disorders of Dementia (ABCD).⁵ Nancy obtained a score of 8 on the immediate story retell task, and a score of 1 on the delayed retell, indicating a mild degree of short-term memory loss.

Learning that Nancy's husband typically visited her in the late afternoons, the SLP left a memory aid information form handout on her bedside table, along with a note for Nancy's husband, asking him to help Nancy fill out the form and requesting his presence at their session the next afternoon.⁶ She also spoke with the nurse on the afternoon shift and alerted her about the forms left in Nancy's room for the spouse.

A Patient-Centered Approach

SLPs have traditionally been trained to use a clinician-focused approach for rehabilitation, consisting of assessing, treating, evaluating outcomes, then discharging. Over the past several years, however, some new models have surfaced, with a focus upon taking the patient's desires into account when formulating a plan of care. As Michelle Bourgeois described, there is a need to "flip the rehab model," particularly when working with individuals with dementia.⁷ Clinicians should focus upon assessing a patient's opinions, desires, and values and what is meaningful to them to develop goals and treatment approaches. At this point, the clinician can determine what functional assessment tools to use to discover barriers, document baseline functioning, and to measure progress or satisfaction.⁷ A similar approach has been developed to measure outcomes in the aphasia population, *Living with Aphasia: Framework for Outcome Measurement*.⁸ This framework captures outcomes by taking the following variables into account:

severity of aphasia, participation in life situations, communication and language environment, and personal identity, attitudes, and feelings. Kagan et al also discussed the importance of discovering what the patient hopes to accomplish at the end of treatment and setting up the appropriate systems to gather this information.⁸

These patient-centered models have been embraced and implemented by some of the leading experts in dementia care around the country. The Cognitive Neurology and Alzheimer's Disease Center (CNADC) at Northwestern Memorial Hospital in Chicago has developed a Care Pathway Model for Dementia program, where the end goal is to enhance quality of life in individuals with dementia by "maximizing independence and safety, identifying helpful modifications to activities and the environment, and providing emotional support" for affected individuals and their families in a multidisciplinary team approach.¹⁰ Weintraub and Morhardt of the CNADC stressed the importance of identifying the unique symptoms that an individual with dementia is experiencing and catering treatment strategies, family education, and resources to meet these individual needs.¹¹ The importance of life participation goals has also been stressed for various types of dementia. Kortte and Rogalski discussed behavioral interventions that may increase participation in meaningful activities for patients suffering from behavioral variant frontotemporal dementia and primary progressive aphasia.¹²

In the sample case study, the SLP utilizes the patient-centered approach in the following manner: first, by addressing Nancy's anxiety regarding her situation by creating a visual memory aid to increase orientation to place, those involved in her care, and the call light; second, by building rapport with Nancy through a discussion regarding her former occupation, her family, and her interests. This discussion shed light upon what Nancy felt was her greatest challenge (word retrieval), in addition to her desire to stay independent, so she could continue to participate in meaningful activities, such as cooking, gardening, and volunteering. The discussion also revealed that Nancy had deficit in short-term episodic memory, which was formally assessed with use

of a brief, but sensitive measure, the story retell test from the ABCD. This short-term memory loss will most likely be the biggest barrier for Nancy to stay independent in the desired activities.

As described later, ongoing dynamic assessment was continued during subsequent treatment sessions, with input from Nancy's husband to further tailor the treatment plan to meet both Nancy and her husband's needs.

Ongoing Dynamic Assessment

The following day, Nancy's husband Robert was present for the speech therapy session. After chatting with Nancy and Robert about their grandchildren for a few minutes, the SLP explained the purpose of the therapy and that they would "work as a team" to find some strategies to help her. Nancy agreed that some strategies would be helpful. A discussion with Nancy and Robert revealed how Nancy's deficits were impacting her daily activities at home:

- decreased ability to managed daily/weekly schedule, including visits with her grandchildren, doctor's appointments, and volunteer events at her church
- difficulty with medication management (Nancy used a pill organizer to sort and take her pills, but occasionally forgot to take her morning pills, particularly if her usual routine was interrupted.)
- frequent misplacement of important items, including her wallet, keys, and cell phone
- difficulty sorting through the daily mail and determining which items to keep and which to throw away
- difficulty with cooking her favorite recipes, meal planning and determining what items to purchase at the store, and sequencing all of the steps to successfully prepare the meals (She frequently forgot steps or overcooked the food.)
- increased difficulty with daily communication due to mild word-finding difficulties

Because of Nancy's decreased insight into her deficits, Robert supplied much of the information during the session. Nancy at times became defensive, saying "I don't have

trouble with that!" It was noted that Robert often argued with her during the discussion, making statements such as, "No, you don't remember the times of your appointments. You asked me four or five times about your therapy appointments today! Do you remember what appointments you went to yesterday?" Nancy became tearful at times, and at one point said, "You don't think I can do anything right anymore!" The SLP intervened and provided counseling during this tense moment, acknowledging both Nancy and Robert's frustrations with the situation and then asked Nancy to elaborate on how she was feeling. The SLP engaged Nancy and Robert in a discussion regarding how Nancy's cognitive changes have impacted both of them and their relationship, along with their traditional roles in the home environment. They were reassured that these frustrations were perfectly normal given the situation and that it is okay to become upset at times. The SLP gave Nancy a hug and comforted her as they discussed the profoundly difficult impact of the Alzheimer's diagnosis on her daily life.

Throughout the evaluation, the SLP ensured that Nancy's dignity was preserved by always looking directly at her during the discussion and never talking about her in the third person. Reassuring statements were made to increase Nancy's participation in the discussion, such as, "Nancy, I really appreciate your feedback about all of this. We're going to try lots of different strategies, and I completely agree that some of them may be helpful while others won't be as helpful. You can decide which strategies will work best for you."

THE ROLE OF COUNSELING IN THERAPY SESSIONS

Counseling and education are integral components of any speech therapy session, regardless of diagnosis. Those individuals suffering from dementia and their family members, however, are especially in need of emotional support at the time of diagnosis and throughout the course of the disease. Audrey Holland discussed the importance of recognizing an opportunity for a "counseling moment" at any point throughout a

treatment session.¹³ Playing the role of the counselor can initially be challenging for some clinicians, as counseling is very different from the usual structured, task-oriented activities that often dominate therapy sessions. When an individual tells a clinician about a problem, many SLPs may make the mistake of immediately trying to offer a solution rather than simply being in the moment, and acknowledging the individual's concerns. The skills of listening, validating, affirming, and comforting all need to be utilized effectively to provide the emotional support that an individual may desperately need.

Education is also an important part of the counseling process, after an individual's emotional needs have been acknowledged and validated. For family members of individuals with dementia, education on the diagnosis, on the rationale behind the treatment approach, and on use of positive communication strategies is essential to promote generalization of treatment strategies and to increase quality of life. For those individuals who demonstrate decreased awareness or are in denial of their cognitive deficits, education of family members is an especially critical component of the plan of care. Oftentimes family members believe that quizzing an individual with memory loss or trying to argue with them regarding their deficits is helpful, when in fact these communication patterns are likely to cause defensiveness and anxiety in the affected individual.¹⁴ It is also important to train family members to determine the emotion behind a question rather than trying to constantly correct or orient their loved one to reality.² For example, when one is constantly asking for a deceased family member, they may be seeking comfort; when asking to go to work, they may be experiencing boredom and are wanting to participate in a meaningful, fulfilling activity. SLPs can help to reduce these negative interactions not only by directly educating family members, but also by demonstrating use of positive communication strategies throughout treatment sessions.

PERSONALLY RELEVANT GOALS

The following goals were selected after the discussion with Nancy and Robert, with a focus

upon training the use of visual memory aids and external devices to help Nancy compensate for her memory loss and aphasia, with constant training of her spouse to ensure generalization of strategies:

- Nancy will recall her location, names/purposes of health care professionals involved in her care, use of call light, and pelvic fracture precautions with use of a visual memory aid, with 90% accuracy in response to open-ended questions, to increase orientation and safety in skilled nursing environment.
- Nancy will recall day, date, and two out of two scheduled activities for the day with use of dry erase schedule board for three consecutive sessions, given minimum verbal cues, for increased schedule management.
- Nancy will utilize visual memory aids and organizational strategies to keep TV remote and cell phone in designated locations, to reduce misplacement of items to less than twice per day for 7 consecutive days, per spouse and staff report using behavior log.
- Nancy will utilize weekly menu planner and grocery list template to plan evening meals during structured tasks, with 80% accuracy, given minimum verbal cues, to increase ability to prepare and cook meals in the home environment.
- Nancy will retrieve the names of important people, places, and items with 80% accuracy during home program targeting the rehearsal of personally relevant information.
- Nancy will recall functional information and personally relevant words in response to open-ended questions with 90% accuracy with use of memory wallet and communication board, given minimum verbal and gestural cues from spouse for initiation.
- Patient's spouse will demonstrate use of positive communication strategies in greater than 90% of interactions, to decrease patient anxiety and to preserve dignity.

PLAN OF TREATMENT

Skilled SLP services were initiated at five times a week, 45 minutes per day. Therapy was recom-

mended for 4 weeks. Robert was asked to attend as many of the therapy sessions as possible.

Treatment began by focusing discussion on general recommendations and safety issues:

- SLP will coordinate with occupational therapy to focus upon organizational strategies and systems for the home environment (e.g., mail sorting) and to focus upon strategies to aid with cooking tasks.
- The following devices were discussed and suggested for purchase:
 - medium-sized dry erase board, to be placed in a prominent spot in the kitchen after discharge
 - large clock displaying the day, date, and time, to be placed next to the dry erase board at home
 - automated pill dispenser (It was decided that Robert would help her to take her pills each day rather than using a pill dispenser.)
- Robert was provided with a handout discussing the use of positive communication strategies for memory loss, such as not quizzing his loved one, avoiding questions that require use of short-term memory, avoiding statements like "You already told me that," and not arguing about her deficits.
- Robert was provided with information regarding a local caregiver support group offered through the Alzheimer's Association.

For subsequent treatment sessions when Robert was present, therapy focused upon strategies and recommendations for the home environment. For treatment sessions without Robert, therapy focused upon the formulation of memory and communication aids, constantly seeking Nancy's input regarding content, and then generalizing use of the aids during conversation/functional tasks. Treatment also focused upon the formulation of a home program targeting the retrieval of personally relevant words.

Specific therapy interventions included the following (see Table 1).

- A "memory station" was recommended for Nancy's kitchen, consisting of her calendar, clock, schedule board, and pill dispenser. Each evening, Nancy and Robert were to write out the schedule for the next day on the

Table 1 Therapy Interventions

Evidence-Based Intervention	References	Personally Relevant Stimuli
Visual memory aids	3,15–19	<ul style="list-style-type: none"> • VMA listing orientation facts/health care professionals, safety precautions • Schedule board listing important activities/appointments • VMA for locations of personal objects • Weekly menu planner and grocery list template • Memory wallet listing names of important people, places, and vocabulary words related to personal interests
Spaced retrieval training	15,20–24	<ul style="list-style-type: none"> • Used to increase Nancy's use of VMAs, including schedule board and memory wallet
Errorless learning	15,25	<ul style="list-style-type: none"> • Used during SRT tasks during therapy and in Nancy's home program targeting the retrieval of personally relevant words
Positive communication strategies	14,26,27	<ul style="list-style-type: none"> • Nancy's husband Robert counseled to use positive communication strategies for memory loss to preserve dignity

Abbreviations: SRT, spaced retrieval training; VMA, visual memory aids.

dry erase board, listing all times and activities. Robert was educated on how to appropriately cue Nancy to refer to the schedule board when she had a question regarding their schedule. Robert brought the dry erase board to the skilled nursing facility to begin implementing its use for schedule management prior to discharge.

- Spaced retrieval training, along with errorless learning strategies, were utilized to train Nancy to refer to the board for her daily schedule, with the prompt "Where would you look to find your daily schedule?"
- Visual memory aids on brightly colored paper were formulated to designate where to place important objects in the skilled nursing environment. Similar aids were made, along with the suggested use of baskets and bowls, to designate locations for Nancy's keys, cell phone, and grandchildren's belongings in the home environment. Robert set up the systems at home to prepare for Nancy's discharge.
- A menu planner and "grocery list" visual memory aids were designed during the therapy session; Robert was trained to provide minimal verbal cues for Nancy to use these aids to plan evening meals
- Personally relevant words and information were also placed in a memory wallet, along with several 8 × 11 visual aids to keep in the kitchen and bedroom. The SLP created all of

these aids with Nancy during therapy sessions using a laptop and Microsoft PowerPoint (Microsoft Corporation, Redmond, WA). Robert was trained to appropriately cue Nancy to use these aids to facilitate recall and word retrieval during conversations.

- Personally relevant words and information were also placed in a memory wallet, along with several 8 × 11 visual aids to keep in the kitchen and bedroom. The SLP created all of these aids with Nancy during therapy sessions using a laptop and Microsoft PowerPoint (Microsoft Corporation, Redmond, WA). Robert was trained to appropriately cue Nancy to use these aids to facilitate recall and word retrieval during conversations.
- The use of positive communication strategies were modeled for Robert during all therapy sessions.

INTEGRATING PERSONALLY RELEVANT STIMULI INTO EVIDENCE-BASED INTERVENTIONS

Table 1 illustrates how the use of personally relevant stimuli was creatively interwoven into the evidence-based treatment plan.

RESULTS

After 4 weeks of treatment, Nancy demonstrated increased independence in the ability to

recall her daily therapy schedule with use of her schedule board. Robert commented that Nancy's repetitive questions about the daily schedule dramatically decreased with use of her schedule board, as documented in the behavior log (decreased from 10 or more times a day to less than three times a day). She misplaced her TV remote and cell phone less frequently in the skilled nursing facility setting with use of visual memory aids and organizational strategies (the certified nursing assistant reporting less than one time a day as compared with five-plus times a day at baseline). She was able to retrieve her personal facts and safety precautions more easily with use of her visual memory aids and memory wallet. Nancy also commented that she looked forward to planning meals after returning home with use of her visual memory aids: the daily meal planner and grocery shopping aid. During structured tasks, Nancy was able to complete the aids given minimal verbal cues from the clinician.

Robert also noticed that Nancy was able to retrieve the personally relevant words targeted in her home exercise program more easily during daily conversations. This subjective report corresponded with accuracies gained during treatment sessions; during the final session, Nancy was able to discuss five of five flowers and herbs that she plants in her garden, as compared with two of five at baseline.

Nancy continued to require consistent minimal cues from Robert to successfully initiate use of the recommended compensatory strategies and memory aids. She continued to demonstrate decreased awareness of her deficits, but participated in the therapy activities because the therapy tasks focused upon content that was of interest to her. Robert demonstrated increased use of positive communication strategies when speaking with his wife, resulting in decreased anxiety and defensiveness. He reported that they got into fewer arguments. During the final treatment session, using a behavior log, the SLP documented only one instance of a negative communication interaction between Robert and Nancy, as compared with five instances at baseline.

Nancy was discharged from skilled speech therapy services in the subacute setting at this point, but SLP spoke with the skilled nursing

facility's social worker to ensure that Nancy would receive speech therapy through home health services upon returning home. The social worker also sent Nancy's therapy records to the home health company to promote generalization of the recommended strategies in the home environment.

CONCLUSION

This case study has illustrated the use of the habilitation approach for a patient in a subacute rehabilitation setting, with a focus upon patient-centered, personally relevant goals and ongoing spouse training to ensure generalization of the strategies in the home environment after discharge. As with all individuals suffering from dementia, one never "graduates" from speech and cognitive therapy, but rather needs ongoing intervals of treatment throughout the progression of the disease. Strategies need to be continuously modified to meet the changing needs of individuals and families coping with these devastating diagnoses. There are four treatment philosophies, however, that should remain constant: (1) ensuring that an individual's dignity is preserved at all times; (2) creating treatment goals that focus upon an individual's unique interests and desires; (3) facilitating an individual's ability to participate in meaningful activities; and (4) involving family members and caregivers in the treatment plan. By placing these four criteria as the foundation of a plan of care, SLPs will have an opportunity to make a significant impact in the lives of individuals and families suffering from dementia.

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