

# International Encyclopedia of Rehabilitation

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# **Improving Quality of Life in Individuals with Dementia: The Role of Nonpharmacologic Approaches in Rehabilitation**

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## **Introduction**

Dementia is a neurodegenerative, progressively deteriorating and terminal clinical syndrome characterized by a loss or decline in memory and other cognitive abilities. Most recent scientific thinking is that dementia may be caused by various diseases and conditions affecting over 5 million Americans (Alzheimer's Association 2008) and 27.7 million worldwide (Wimo et al. 2006). It is projected that the number of Americans with dementia will exceed 7.7 million by the year 2030 and from 11 to 16 million by the year 2050 (Alzheimer's Association 2008). There is presently not a cure for dementia.

The most common form of dementia is Alzheimer's disease, accounting for up to 80% of cases. Other common forms of dementia include vascular dementia, mixed dementia, dementia with Lewy Bodies, Parkinson Dementia, Frontotemporal dementia, or Creutzfeldt-Jakob's Disease. Although promising experimental treatments are currently

undergoing animal and human testing, experts agree that a cure or specific treatment to slow or arrest disease progression will take many more years of research. Thus, developing, testing and implementing nonpharmacologic approaches in clinical settings to manage the disease and that support or enhance quality of life for individuals with dementia and their families, is a public health imperative both in the United States and worldwide.

The primary goal of rehabilitation is to enable people to achieve their optimal level of function. Thus, as suggested by Cohen and Eisdorfer (1986) and others, rehabilitation is an appropriate framework within which to think about dementia care. The primary focus of rehabilitation for the dementia patient is on habilitative, compensatory, nonpharmacologic approaches that modify behaviors and/or the physical and social environment to help individuals cope with the disease and continue to participate in everyday activities of living for as long as possible. The focus is strength based, and draws upon the preserved capabilities of the individual to help them achieve quality of life regardless of level of cognitive status. This is in contrast to traditional restorative therapies in rehabilitation which seek to address, cure or minimize impairment or address the underlying pathophysiologic or neurological level to attain improvements in status.

The three principal goals of rehabilitation for individuals with dementia are to: 1) help the individual maintain or improve function and engage in daily activities to the extent possible and as the disease progresses; 2) restore or compensate for functional decline due to an acute insult such as an injury or traumatic health episode such as a stroke, or fall which occurs over and above the dementia; and 3) provide family caregivers with education and knowledge about the disease and specific skills to provide a supportive environment at home and reduce excess disability (Reifler and Larson 1990).

Due in part to the fact that dementia is a terminal condition, healthcare professionals have not traditionally considered dementia patients as appropriate candidates for rehabilitation. Most health professionals remain unaware of how best to support this clinical population, how to effectively engage individuals with dementia in rehabilitative therapies to address acute more traditional rehabilitative conditions, and the significant role of an habilitative framework in enhancing the quality of life for this population.

The purpose of this chapter is to advance the role of nonpharmacologic approaches in rehabilitation for the clinical management of dementia patients. We first identify common challenges that emerge when working with individuals with dementia and offer practical solutions. Next, because dementia follows a complex trajectory, it requires the input and perspectives of multiple health professions. Thus, we present the concept of the interprofessional healthcare team for dementia care, describe its unique characteristics, and the respective roles of team members. We then discuss emerging evidentiary-based nonpharmacologic practices that can be used by rehabilitation specialists and integrated into traditional services to enhance the quality of life of individuals with dementia and their families.

## **Challenges Working with Individuals with Dementia**

Dementia patients in rehabilitation present unique challenges in the therapeutic process due mostly to the hallmark cognitive changes and memory loss associated with the disease. Three primary concerns in the rehabilitation context include: 1) the extent to which new learning is possible such that new techniques, therapies or compensatory strategies, particularly those involving behavioral change to address functional or performance difficulties, can be effectively introduced and successfully used; 2) how to effectively contend with dementia-related behaviors that can disrupt or interfere with therapeutic processes and rehabilitative goals; and 3) approaches to effectively involve family members in the therapeutic process to maximize benefit for individuals with dementia.

### **New Learning**

Memory and learning are closely associated and difficult to differentiate. Learning involves the acquisition of new information which changes the individual's knowledge or behavior. Memory includes the retention of that information. Hence, learning is dependent upon memory, and memory can not exist if informational processing (learning) fails to occur.

Memory impairment affects behavior and daily performance capabilities, and in dementia, it interferes with the ability to learn. Deficits are most severe in short-term working memory and long-term memory (episodic and semantic). Executive functioning skills, which are activated in short-term working memory, are severely impaired in individuals with dementia such that it affects the ability to retain information long-enough to transfer it into long-term memory. This in turn reduces the capacity for new (episodic) learning. However, new learning impairment does not necessarily apply to *procedural memory* capacities, especially in the early to moderate disease stages. Current research suggests that individuals with significant cognitive impairment due to dementia-related disorders can “learn” using procedural memory (Camp et al. 1996).

In dementia, procedural memory is the most sustaining memory store, due to the slower rate in deterioration compared to episodic and semantic memory. It is an area of preserved cognitive capacity which facilitates learning and can support rehabilitation goals. Procedural memory involves a combination of motor, perceptual, and cognitive skills associated with attainment of movement. Through repetition and practice, these “over-learned” skills evolve into memories that are processed automatically. The patient interacts with the environment more efficiently with minimum cognitive effort (Levy 2006). Procedural memory-based training has the potential of generating positive effects on behavioral and functional change with this population. By providing effective environmental cues to prompt this memory system, rehabilitation specialists are able to facilitate relearning of familiar, meaningful, procedural skills necessary for daily functioning. New learning is maximized when environmental cues are matched with the individual's level of cognitive functioning (Levy 2005). Thus, identifying an individual's cognitive capabilities and limitations is pivotal to ensuring safe functional performance.

One approach to identifying cognitive capabilities is a systematic, and standardized set of performance-based assessments (Allen Cognitive Level Screen and Allen diagnostic Module) used by occupational therapists. The assessments yield a score reflecting functional capacity along a hierarchy of six functional levels (1=profoundly disabled to 6=intact executive functioning), and within each level, sublevels (sequential modes of performance) reflecting gradations of abilities (Allen 1985; Allen et al. 2007; Earhart 2006). This offers therapists a fine-grained and in-depth understanding of not only deficit areas but also specific abilities in performing functional activities and the most effective approaches for engaging the individual in everyday activities (Gitlin et al. 2008).

Despite the level of cognitive functioning, informational processing (learning) can be optimized if a therapeutic intervention is based upon an understanding of the individual's capabilities. Once an occupational therapy evaluation has established an individual's cognitive level and functional capabilities, a customized intervention plan can be designed. Rehabilitation strategies to facilitate compensatory learning include: modifying environments, simplifying tasks, establishing structure and routine, practicing concrete tasks through repetition and practice, providing task-specific training, using "hands-on" teaching techniques, utilizing effective cueing and communication strategies, skills-training and education of family caregivers. It is recommended that rehabilitation specialists incorporate these supportive strategies with their patients with dementia thus activating procedural memories for new learning in order to maximize full rehabilitation potential.

## **Behavioral Symptoms**

Behavioral symptoms, referred to as the secondary manifestation of the disease process, are common in individuals with dementia and can occur throughout the course of the disease. Most individuals with dementia manifest at least one or more behavioral symptoms, with agitated-type behaviors being the most typical (Lyketsos et al. 2001). Behavioral symptoms have a profound effect on individuals with dementia and their family members, compromising life quality, heightening caregiver burden and risk for nursing home placement, and increasing time spent in caregiving and health care costs (Ballard et al. 2000). Even passive behaviors (withdrawal, apathy) are reported by families as sources of great frustration and sadness (Colling 2004).

In the therapeutic context, common behavioral symptoms may include resistance, verbal or physical aggressiveness, agitation, and refusal to engage in the therapeutic session. To help patients achieve rehabilitative goals, it is important to understand why such behaviors may occur and ways to minimize or manage them.

It is unclear as to the etiology of dementia-related behaviors and their relationship to the underlying pathology (Swearer et al. 1988; Schneider et al. 1990; Swanwick 1995; Colenda 1995; Finkel and Burns 2000). Although some studies show that the prevalence and severity of behaviors increase with global severity of dementia, other studies suggest a non-monotone pattern with the most disturbing behaviors (aggressiveness) occurring at the moderate stage of the disease and diminishing with disease progression (McCarty et al. 2000; Gitlin et al. 2007). Nevertheless, research suggests that behavioral symptoms

cannot be explained solely by diminished cognitive capacity. Rather, behaviors may reflect the interplay or interaction between the pathology, a person's capabilities and the physical and social environment in which behaviors occurs (Moniz-Cook and Vernooij-Dassen 2006; Cohen-Mansfield 2001; Mittelman 2000; Boucher 1999; Gitlin et al. 2007).

Efforts to manage behaviors, particularly agitation, aggressiveness, and hallucinations/delusions, typically have involved pharmacologic treatments, specifically the off label use of atypical antipsychotic drugs (Salzman et al. 2008). Yet, these pharmacologic approaches have been shown to yield only modest benefit, and at some considerable risk (Burton et al. 2005; Ownby et al. 2001, Salzman et al. 2008; Schneider et al. 2005; Schneider et al. 2006; Selback et al. 2007; Sink et al. 2005; Tariot 1999; U.S. Food and Drug Administration Public Health Advisory 2005). Recent evidence has led the Federal Drug Administration (FDA) to enforce a black box warning such that manufacturers must state that these medications may cause death in the elderly with dementia. There is also emerging evidence that nonpharmacologic treatments compare favorably even when a pharmacologic solution exists (Bird et al. 2007; Monette et al. 2007; Teri et al. 2000). While a pharmacological approach may help manage certain psychiatric behaviors (e.g., hallucinations, paranoia, or mood disorders such as depression), common behavioral disturbances that occur in the therapeutic context or at home with families such as wandering, resistance, agitation, or repetitive vocalizations, are much less amenable to drug management (Class et al. 1997). Thus, there is considerable and increasing interest in the potential of nonpharmacologic interventions (Clarfield 2001; Iliffe et al. 2006; Moniz-Cook and Veroonij-Dassen 2006; Swanwick 1995). Recent consensus and white paper reports from organizations such as the American Association for Geriatric Psychiatry, American Society of Neuropsychopharmacology, and the 2006 Geriatric Mental Health Expert Panel, have recommended that nonpharmacologic approaches serve as the initial treatment of choice prior to considering drug therapies (American Association of Geriatric Psychiatry 2005; American Psychiatric Association Work Group on Alzheimer's Disease and other Dementias 2007; Lyketsos et al. 2006; Salzman et al. 2008).

## **Frameworks for Understanding Behaviors**

To understand how a nonpharmacologic approach may be helpful, we draw upon various environmental vulnerability frameworks. One conceptual model, the Progressively Lowered Stress Threshold (PLST) proposes that with disease progression, individuals with dementia experience increasing vulnerability and a lower threshold to stress and external stimuli. One source of stress is the environment including daily routines, activities, and interactions with caregivers (formal and informal). As the day progresses, there is an accumulation of stress imposed by the demands of the environment (Hall and Buckwalter, 1987; Richards and Beck 2004). PLST suggests that minimizing environmental demands that exceed functional capacity and regulating activity and stimulation levels throughout the day can reduce agitation. Complementing this framework is the Competence-Environmental Press Model (CEPM; Lawton and Nahemow, 1973) which suggests that there are optimal combinations of environmental circumstances or conditions and personal competencies that result in the highest possible

functioning for individuals. Obtaining the just-right-fit between an individual's capabilities and external demands of environments/activities results in adaptive, positive behaviors; alternately, environments/activities that are too demanding or understimulating may result in behavioral symptoms such as agitation or passivity in individuals with dementia. Similar to PLST, the CEPM suggests that environments/activities can be modified to fit any level of cognitive functioning and individual competencies in order to optimize quality of life. Both frameworks suggest that behaviors can be reduced or managed by modifying contributing factors that place too much demand or press on the individual with dementia. Such factors may include the physical environment (e.g., auditory and visual distractions), the social environment (e.g., communication style of informal/formal caregivers), or factors that are modifiable but which are internal to the individual themselves (e.g., discomfort, pain, fatigue) as described in more detail below.

### **Managing Behavioral Symptoms in the Therapeutic Context**

In the context of rehabilitation therapies in the home or clinic, behaviors can be particularly disruptive and prevent the full participation of an individual with dementia in therapeutic processes that are designed to address immediate functional concerns. Thus, therapists must learn techniques to manage manifested behaviors not only to achieve immediate therapeutic goals, but also, to reduce the upset and potential danger of such behaviors to the individual with dementia and their family members. As the above frameworks suggest, viewing behaviors as an outcome of the interaction between the person and the physical and social environment is helpful for understanding why a particular behavior may be occurring and the specific factors that may be contributing to their occurrence (Gitlin and Corcoran 2005). Key person-based contributors to behaviors in the rehabilitation context may include; a) pain which the individual is unable to identify, understand or articulate as occurring; b) fatigue, poor sleeping patterns; c) fear, anxiety, or sense of a loss of control; d) misunderstandings of the therapeutic process and anxiety as to what is expected; e) underlying incipient medical conditions such as an infection (e.g., urinary tract infection); f) clinical depression or psychotic symptoms (hallucinations); g) significant sensory changes (e.g. reduced visual efficiency, hearing loss, decline in somatosensory system); h) constipation; or i) dehydration. Key environmental-based factors contributing to behaviors may include; a) a physical environment such as the home or clinic that is too cluttered, distracting and difficult to navigate; b) a physical environment that is unfamiliar or too complex such that the person has difficulty interpreting the meaning of environmental cues and thus responding appropriately; c) presence of others during therapeutic sessions which may be distracting, confusing, and a sensory overload; and d) communication patterns that are too complex and confusing.

Communication in particular is a primary contributor to behavioral outcomes (Williams et al. 2008). For example, speaking “down” to a person, using infantilizing communication, overly complex commands or explanations, having a stern or agitated voice, speaking too quickly or not allowing time for the individual to process information, and/or rushing through a therapeutic activity are all common

communications among healthcare providers that can contribute to resistance and agitated-type behaviors and heighten feelings of confusion, fear and anxiety.

Hence, one of the most powerful and immediately effective approaches to minimizing behavioral symptoms when working with individuals with dementia is adapting an effective communication style. Dementia can cause difficulties in how an individual communicates to others and how the person understands the rehabilitative process. It can also affect the way he/she performs an action or movement (unable to bring a spoon to mouth). Individuals with dementia may not be able to perform a particular action due to the dementia (e.g., they may not remember how to use utensils anymore, or they may have initiation or sequencing difficulties). Processing difficulties can be minimized by providing specific types of “cues”. A cue is a signal, such as a word or action, used to prompt performance. A cue can be a verbal command, a visual prompt, or a tactile/physical prompt such as gently guiding the body through the movement. The use of one or more “cues” to assist in the performance of a specified therapeutic task, can be highly effective. Regardless of the cues that are used, individuals with dementia need sufficient time to understand and process instructions and the specific content that is being communicated.

Individuals with dementia may respond differently to various cues and thus their use requires some trial and error. Below are cueing strategies that may be helpful to a person to help them initiate action. It is helpful to begin with verbal cues, and if not successful, to then add visual cues, followed by tactile cueing if necessary. For example, verbal cueing should consist of one or two simple verbal commands. It is important to use very specific verbal prompting that clearly instructs the individual to perform the specific steps of an activity. For example, if the individual needs to stand up from the bed to walk to the bathroom, the following verbal cues can be introduced one at a time using a calm voice and speaking slowly:

- Roll to the left
- Sit up
- Hold onto the bedpost
- Stand up
- Great job

For some individuals at the moderate to severe stage, it may be necessary to limit the amount of words used in verbal directions given that language can become confusing at this disease stage and individuals may have significant difficulty processing words. Using signals other than words such as pointing, touching or handing objects to help direct individuals can be effective. For example, one can point to an object to have the individual use it (e.g., point to a spoon so the individual reaches the correct utensil; or only place a spoon within the visual field of the individual and remove all other objects/utensils), or tap on a drinking glass to turn the individual’s attention to drink.

Demonstration can also serve as an effective visual cue. By being positioned within an individual’s visual field so that he/she can observe a particular action (e.g., the therapist

drinking from the glass), may help that person imitate the actions. If verbal and visual cueing are unsuccessful, tactile cueing may be effective. Some individuals with dementia work best when they are provided with gentle physical assistance to complete an action. Hand-over-hand assistance may provide information to the nervous system so that the individual can successfully complete the task. For example, using a light touch, the therapist can place their hand over the patient's hand (holding the spoon) and initiate the motion of self-feeding. Hand-over-hand cueing serves as a reminder/prompt. Table 1 lists the key elements of effective communication.

### **Table 1: Effective Communication Strategies with Individuals with Dementia**

- Move and speak slowly and calmly
- Provide 1 to 2 step simple verbal instructions at a time
- Do not rush.
- Allow patient sufficient time to respond to a command
- Reassure patient that they are doing a good job
- Avoid use of negative words and negative approaches (Don't scold, argue)
- Eliminate noise and distraction while communicating
- Be aware of facial expressions, make eye contact but do not stare
- Express affection – smile, hold hands, give a hug

### **Involving Family Caregivers**

Although the traditional focus of rehabilitation is on the impaired person, in individuals with dementia, this focus needs to be broadened to include informal caregivers as well. Critical to successful rehabilitation is the involvement of the family, defined as family, friends or neighbors involved in daily support or direct care. Engaging family members in the therapeutic process is important to: a) assure carryover of specific therapeutic strategies from the clinic to daily routines at home, b) help families understand dementia and how to manage day-to-day, c) enhance the family and patient's quality of life, and d) provide support to a family member who may be overwhelmed or depressed. Moreover, family caregivers, sometimes referred to as proxies, collaterals or key informants, can provide essential knowledge about the person with dementia to inform the therapeutic process and provide feedback about the level of therapeutic success that is achieved.

The inclusion of families in rehabilitation has typically been viewed as challenging and time consuming by therapists. This is particularly the case when a family member is reluctant to participate, presents different goals and objectives than that endorsed by the patient and/or healthcare team, or when there is conflict among family members that effects healthcare decision-making. Nevertheless, given that families remain at the forefront of caring for individuals with dementia for the duration of the disease, involving the family in rehabilitation and seeking an understanding of their own abilities, emotional well-being and goals for care are critical to the success of the therapeutic process.

Of importance is that family caregivers are often the neglected and hidden patients themselves. Assessment of caregiver needs rarely occurs and most providers do not even ask the simple question "How are you doing?" Moreover, the health and well-being of a

family caregiver has a direct bearing on the quality of life and success of therapy for dementia patients. Research shows for example, that dementia patients have higher rates of behavioral symptoms and mortality when cared for by families who are stressed, use emotion-based coping (e.g., wishing the disease would go away), or negative communication strategies (McClendon et al. 2004).

One effective approach by which to involve family members is to establish a collaborative relationship in which the family is viewed as an equal partner and member of the healthcare team (Gitlin and Corcoran 2004). This entails using active listening and systematically assessing the care goals of the family and their own concerns and abilities to reinforce therapeutic strategies. Incorporating the knowledge and input of the primary family caregiver or other members of the patient's network, as part of the deliberations of the healthcare team can enhance treatment success.

Expanding the focus of rehabilitation to the dyad necessitates the systematic assessment of the family caregiver with regard to the different areas for which they may be at risk including whether there are home safety concerns, whether they need education about the disease and specific skills to manage behaviors, and the extent to which the caregiver is emotionally upset, overwhelmed or depressed (Belle et al., 2006). Brief validated risk questionnaires are available to help rehabilitation therapists quickly identify caregiver needs and potential effective intervention strategies (Czaja, et al., 2008). Even making referrals to other health and human service professionals to address family concerns, needs, risk areas can be an important part of the rehabilitative process. For example, a home safety check, referral to a counselor or physician to address depression, recommendations to join a caregiver support program, or referral for in-home skills training may be appropriate and should be considered an essential part of the rehabilitation process for individuals with dementia.

### **Interprofessional Healthcare Team**

Due to the complexities of Alzheimer's disease and related disorders, assessment, intervention and caregiver support can be more effective when the healthcare team uses a collaborative, interprofessional approach in rehabilitation. *Interprofessional teams* are groups of healthcare professionals who work together closely and contribute their unique expertise and experience to develop an integrated approach to understanding and treating an individual with a health problem (Bensing 2005). Unlike the multidisciplinary framework, members of an interprofessional team communicate with each other on a regular basis and work to frame a common understanding of the health problem and treatment goals. Research shows that such collaborative team approaches lead to improved patient care and outcomes, and more effective use of health resources (Ontario Hospital Association 2008).

Using an interprofessional approach for dementia care fosters team problem-solving, better morale and coordination among team members. Highly functioning interprofessional teams demonstrate an appreciation, respect, and understanding of other allied professionals as well as the contribution of the family caregiver, who is viewed as an integral part of the interprofessional team. Team collaboration involves the

caregiver's perspective which helps direct the overall care and is fully represented in the intervention process. As discussed earlier, caregiver "buy-in" and input are essential to assure follow through of the rehabilitation strategies, especially once the individual is discharged home.

An interprofessional team approach necessitates understanding and knowledge of each team member's role and responsibilities. Table 2 highlights the unique roles and responsibilities of each team member in the care of the dementia patient.

**Table 2: Roles and Responsibilities of the Interprofessional Team in Dementia Care**

Discipline	Role in Dementia
Nurse	Provide personal care, and assist in activities of daily living. Manage illness related symptoms. Perform prescribed treatments and give medications with knowledge of actions, interactions, and polypharmacy issues. Provide milieu for therapeutic communication and coping strategies. Advocate for patients. Teach families, caregivers and patients. Develop care plan in collaboration with interprofessional team members and access various resources available for patients.
Nurse practitioner	Provide uncomplicated ongoing health care and collaborate with physicians and other disciplines to develop plan of care. Provide educational sessions to staff about caring for person with dementia. Provide counseling sessions or facilitate support groups for family members
Primary Care Physician	Recognition of change in cognitive function; routine diagnostic evaluation, counseling of patient and family, initiate and or monitor medical therapy. Refer to specialized medical health professions and community resources and provide longitudinal support for patient and family.
Geriatrician	Provider expert evaluation, diagnosis and management of unusual or complex dementia presentations; special expertise in managing behavioral symptoms and co morbid illness; expert in community resources home care and residential care settings. Ongoing support for pt/family.
Geriatric Psychiatrist	Expert in evaluation and diagnosis of full spectrum of cognitive disorders and behavioral manifestations of dementia and related psychiatric disorders. Recommends and monitors medication therapy, counsels pt/family and coordinates with other providers overall plan of care.
Physician assistant	Under the supervision of a physician; recognition of change in cognitive function; routine diagnostic evaluation, counseling of patient and family, initiate and/or monitor medical therapy. Refer to specialized medical health professions and community resources and provide longitudinal support for patient and family.
Social Worker	Conduct comprehensive, strengths-based assessment of individual and caregiver to develop care plan. Link to community resources to address unmet needs. Coordinate community care with hospital and nursing facility discharge planners. Provide case management. Educate and counsel throughout disease process. Advocacy activities per need. Establish and facilitate client and caregiver support groups.
Psychologist	Perform neuropsychological assessments for mild cognitive impairment or dementia. Provide psychotherapy & group therapy. Provide end-of-life counseling.
Pharmacist	Optimize pharmacotherapeutic regiment to reduce or eliminate dementia causing drugs. Recommend therapeutic options and monitor for adverse effects. Provide medication related information patient and caregiver. Provide assistance for improving medical adherence.
Occupational Therapist	Evaluate preserved capabilities and functional performance and determine the type of assistance, compensatory strategy, and environmental modification needed to successfully & safely complete activities. Provide caregiver training in problem-solving, task simplification, communication, & stress-reduction techniques to ease caregiver's burden.
Physical Therapist	Provide interventions such as education and training to both the person with dementia and the caregivers to maximize ADLs, function and mobility, promote a safe environment, and to reduce risk of injuries and falls. Work effectively with the interdisciplinary team, to support the highest attainable quality of life for the person with dementia and the caregivers.
Chaplain	Chaplains should advise caregivers to express their feelings through compassion, commitment, and humble entry into the culture of dementia. <a href="http://www.agis.com/Document/152/dementia-ethical-issues.aspx">http://www.agis.com/Document/152/dementia-ethical-issues.aspx</a>
Dietitian	Encourage independent eating, educate on the importance of fluid intake, and provide foods that are ethnically and culturally appropriate. <a href="http://alzheimers.about.com/od/practicalcare/a/Alzheimer_Diet.htm">http://alzheimers.about.com/od/practicalcare/a/Alzheimer_Diet.htm</a>
Family Member of choice (Caregiver)	Provide nuances of behavior and physical states of person with dementia. Help team define realistic goals. Shares effective strategies for interacting with patient Caregivers can sense how receptive patient will be with treatment plan.
Patient (early stages of Dementia)	Provides insights on his/her daily routines, needs, abilities, interests, preferences

Characteristics of an effective collaborative, interprofessional team include the following (GITT Resource Center, 2001):

- Coordinated care among clinicians and patient/caregiver
- Clear, open communication, including active listening, between all team members
- Interprofessional team exhibits knowledge and understanding of the family's need
- Problem-solving is conducted between at least 2 members
- Commitment to learn values and knowledge bases of other professions
- Consistent, ongoing organizational and team philosophy about dementia care

### **Promising Nonpharmacologic Rehabilitative Approaches**

Various nonpharmacologic therapeutic approaches are available to help manage complex behaviors and improve the quality of life of persons with dementia. Nonpharmacologic approaches are wide ranging and may include environmental redesign, purposeful use of music, touch and/or other sensory-based strategies, caregiver training, exercise, use of pleasant events and activity engagement, and cognitive therapies (Cohen-Mansfield 2001; Cohen-Mansfield 2005; Gitlin and Corcoran 1993; Lodgson et al. 2007; Zeisel 2006). Nevertheless, reviews of nonpharmacologic studies uniformly suggest that such approaches are promising but that more rigorous research is required (Ayalon et al. 2006; Gitlin et al. 2003). The research continues to be limited by small sample sizes, small effect sizes, single case study designs, lack of methodological rigor, and a focus on nursing home residents.

Despite the need for more research in this area, there are emerging evidence-based therapeutic approaches that can become part of the therapeutic tool kit of rehabilitation specialists and which research is showing results in quality of life benefits for both patients and their family members. Table 3 summarizes 9 key approaches with emerging evidentiary support and a brief explanation of each.

**Table 3: Potential Nonpharmacologic Approaches in Dementia Care**

Approaches/Programs	Description	Key Citation
Cognitive rehabilitation	Cognitive rehabilitation focuses on enabling people to engage in everyday activities and identifying specific strategies for dealing with difficulties resulting from changes in memory or other cognitive domains. Different techniques are used including spaced retrieval, identifying compensatory strategies, or altering the environment so as to better support cognitive functioning.	(Camp 1999; Camp et al. 2000),
Caregiver training	Caregiver training focuses on providing families with the requisite knowledge about dementia and specific strategies including problem-solving, communication techniques and simplification approaches to manage daily care challenges as well as cope with their own emotional responses and stressors.	(Gitlin and Corcoran 2005; Mittelman 2000; Belle et al. 2006)
Environmental redesign	Use of design principles to minimize environmental stress and enhance functionality of persons with dementia. Principles such as simplification, color coding, visual cueing, placing objects in sight or out-of-sight are used.	(Calkins, 2006; Gitlin et al. 2003)
Activity engagement	Engagement of patients in activities graded to capabilities including pleasant events, crafts, exercise.	(Gitlin et al. 2008; Cohen-Mansfield, 2001 ; 2005; Teri et al. 1997)
Memory boards	Use of memory boards for cueing and orientation	(Bourgeois, 2007)
Cognitive behavioral therapy to address anxiety (CBT-AD)	CBT-AD integrates empirically supported interventions for late-life anxiety with strategies that facilitate comprehension, encoding, and retrieval for people with dementia (e.g., memory cueing, spaced retrieval). Treatment components include awareness training, breathing skills, coping self-statements, behavioral activation, and sleep skills. Collaterals (a family member, friend, or caregiver who spends at least 8 hours a week with the patient) participate as ‘coaches’ in assessment and treatment, and the intervention is conducted in the home. Up to 12 in-person sessions are offered over a 3-month period, followed by 8 subsequent telephone contacts over a second 3 months.	(Kraus et al. 2008)

Hallmark characteristics of the nonpharmacologic approaches listed in Table 3 include:

- a. customization or tailoring to match the capabilities and environmental context of the dementia patient;
- b. involvement of the family and provision of family education and support;
- c. use of problem solving to identify modifiable factors contributing to behavioral disturbances or excess disability;
- d. use of simplification strategies (communication, environment, or tasks) to allow for engagement or enhanced information processing on the part of the dementia patient; and
- e. use of a habilitative versus restorative framework for treatment. Another common element of these approaches is a focus on the social and emotional consequences of the disease process.

One promising nonpharmacologic approach particularly relevant to the rehabilitation context is activity (Brooker et al. 2007; Buettner 1995; Buettner et al. 1996; Clark et al. 1997; Fitzsimmons and Buettner 2002; Kolanowski et al. 2006; Teri and Logsdon 1991; Teri et al. 1997; Yu et al. 2006). Consistently positive benefits have been shown for the therapeutic use of activities with nursing home residents such as reduced agitation, decreased restraint and pharmacological use, and enhanced life quality (Brooker and Woolley 2007; Orsulic et al. 2000; Rovner et al. 1996). Research also suggests that activity engagement is an important source of meaning to patients, providing a positive emotional outlet and sense of involvement and belonging, and preserving personal identity (Phinney et al. 2007). In one of the few well-designed studies using a randomized design with 153 community-dwelling patients, Teri et al. found that exercise plus caregiver training in behavioral management improved physical health and depression in patients (Teri et al. 2003). In another well-controlled clinical trial with 72 dyads, Teri and colleagues found that two different nonpharmacologic approaches effectively reduced patient depressive symptoms; one intervention involved problem solving with caregivers concerning patient behaviors; the other introduced pleasant events for the patient (Teri et al. 1997). In a randomized trial with 60 patients, Gitlin and colleagues (2008) found that the Tailored Activity Program (TAP), an intervention that engages patients in activities tailored to their capabilities and trains family caregivers in using activities in everyday care, reduced behavioral symptoms and caregiver time spent in daily care, and enhanced caregiver skill and confidence.

Use of activity within the rehabilitative context can be highly effective to even achieve physical goals. However, for effective engagement to occur, activities must be tailored to the particular individual's preserved capabilities and interests based on systematic assessment.

## **Conclusion**

In summary, rehabilitation has much to offer individuals with dementia and their families. This clinical population can positively respond to traditional rehabilitative techniques to address acute functional issues as well as habilitative approaches that are designed to support daily function and quality of life throughout the course of the disease.

Rehabilitation in both cases can be effective if therapists bring to the treatment context an understanding of the person and their environment, use effective communication strategies, providing a supportive and simplified environment in which new learning and tasks occur, and offering caregiver education, support and training. Presently, we lack an appropriate healthcare system infrastructure involving referral and reimbursement mechanisms in which individuals with dementia can receive on-going rehabilitative supportive services to achieve a better life quality. Policy advocacy for advancement of new models of coordinated and nonpharmacologic rehabilitative care systems that address the pressing needs of the dyad (individual with dementia and their family member) are imperative in order to respond to the increasing number of individuals living in the community with this devastating disease.

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