

Perspective

## Leveraging Existing Abilities in Dementia (LEAD™): Changing the Way Rehabilitation Professionals Care for Persons Living with Dementia

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**Academic Editor:** R. M. Damian Holsinger

**Special Issue:** [Alzheimer's Disease: Current Knowledge and Future Perspectives](#)

*OBM Geriatrics*

2024, volume 8, issue 2

doi:10.21926/obm.geriatr.2402275

**Received:** December 08, 2023

**Accepted:** March 25, 2024

**Published:** April 03, 2024

### Abstract

Latest estimates indicate that 5-7% of the population are living with Alzheimer's disease and related dementias worldwide with a doubling in incidence expected every 20 years. Rehabilitation professionals are challenged with the complex needs of these patients. It is commonly thought that patients with dementia do not benefit from rehabilitation because of cognitive decline, behaviors, lack of communication, or difficulties in learning; however, current literature indicates this is not accurate. With proper knowledge and training, rehabilitation professionals can provide dementia-specific, person-centered care to maximize rehabilitation outcomes by maintaining or even improving function and thereby reduce healthcare costs. This article introduces an innovative rehabilitation framework, Leveraging Existing Abilities in Dementia (LEAD™), which was developed using tenets of the Strength-Based Approach to assist clinicians with the necessary education and skills for working with this specialized patient population. The LEAD™ framework guides the therapist in



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understanding how the disease process can impact the individual while identifying current strengths and abilities across several key areas allowing the rehabilitation professional to best identify appropriate treatment strategies. Treatment strategies and facilitators are described in three key areas (the '3 C's): communication, cognition, and coping. The LEAD™ Framework for Rehabilitation Professionals aims to address the current barriers to care, such as lack of general knowledge about dementia, how to manage cognitive and emotional behaviors related to dementia, and limited understanding of how to communicate and engage with these patients. This type of guidance for daily practice is needed for these unique patients with hopes of further research.

### **Keywords**

Dementia; strength-based; cognition; rehabilitation

## **1. Introduction**

As the number of older adults with dementia continues to grow [1], it is likely that rehabilitation professionals including physical therapists, occupational therapists, and speech language pathologists will provide care to a person living with dementia (PLWD). As such, rehabilitation professionals are challenged with understanding the complex care needs of patients living with a progressive neurodegenerative disease. In a recent study by the American Occupational Therapy Association jointly with the American Physical Therapy Association, it was noted that 45% of the Medicare beneficiaries receiving rehabilitation in a skilled nursing facility have Alzheimer's disease or a related Dementia [2]. Since there is no cure for dementia and there are no medications which have been proven to halt the progression of these illnesses [3, 4], these rehabilitation professionals are critical in providing impactful non-pharmacological care to older adults with dementia. Physical, occupational, and speech therapists work together as part of an interdisciplinary team that includes other critical members. Nurses, psychologists, medical staff, and social workers along with rehabilitation professionals provide support to the patients and their caregivers along the continuum of care. This paper introduces an evidence-informed and pragmatic framework for addressing current barriers for rehabilitation professionals when working with PLWDs.

The framework, **L**everaging **E**xisting **A**ilities in **D**ementia (LEAD™), builds upon prior research findings indicating: 1) the positive impact of dementia education and training programs for nursing staff and informal caregivers [5-12]; 2) PLWDs can benefit from rehabilitation as much as individuals without dementia [13, 14]; and 3) the importance of utilizing a person-centered approach that focuses on understanding the needs and abilities of the individual within their current environment [5, 8-11]. The framework also addresses barriers reported by healthcare providers, including rehabilitation professionals, in working with PLWDs, such as lack of dementia knowledge and confidence in daily practice, management of cognitive and emotional behaviors related to dementia, and limited understanding of how to communicate with and engage with these patients [6, 15-19].

**L**everaging **E**xisting **A**ilities in **D**ementia (LEAD™) is based on the dyadic psychosocial intervention, **A**cquiring **N**ew **S**kills **W**hile **E**nhancing **R**emaining **S**trengths (*ANSWERS*) [20], and integrates tenets from the Strength-Based Approach [20, 21] along with keys concepts from the

information processing model [22-24]. The information processing model is a theoretical framework used in Cognitive Psychology outlining how information is processed through sensory memory, short-term memory, and long-term memory systems and was used to provide a guide for understanding how dementia differentially impacts cognitive processes. The Strength-Based Approach consists of the following tenets: 1) identifying strengths and abilities rather than deficits and limitations; 2) including individuals as active rather than passive participants in treatment; and 3) emphasizing current possibilities and options rather than past events and performance. By identifying strengths and current possibilities, rehabilitation professionals can provide challenge to a meaningful task that can be successfully completed by the individual while compensating for impaired processes that previously may have been barriers to successful treatment. Furthermore, it is possible that implementing these strategies in rehabilitation interventions may improve adherence, enjoyment in participation, and general outcomes due to its specificity of capitalizing on person-centered strengths allowing PLWDs with a range of severity to maintain a level of activity within their own care [25].

Studies using a Strength-Based Approach have found promising results. Project *ANSWERS* provided both the PLWD and their caregiver with a core set of skills for managing and coping with the symptoms of mild-to-moderate dementia [20]. Results found significant improvements for caregivers and individuals with mild to moderate dementia across several measure of care-related strain and psychosocial well-being [25]. Additionally, the Strength-Based Approach was used in the implementation of a home-based moderate-intensity strength and balance exercise program for individuals ranging from mild to severe dementia that demonstrated excellent adherence along with efficacious results in strength, balance, and fast gait speed [26]. The Strength-Based approach also has been recently applied to vestibular rehabilitation with PLWDs [27] as well as providing guidance and pragmatic ideas for physical therapists working with individuals living with dementia [28]. Lastly, a training program teaching the LEAD™ framework was found to be successful in improving confidence and upgraded practice patterns in service provision for patients with dementia in home health therapists [12]. The LEAD™ training program includes educational information about dementia and the impact across multiple domains of function including cognition, physical performance, and psychosocial well-being in addition to specific treatment strategies to enhance success.

## **2. Viewing Dementia Using the Information Processing Model and the Strength-Based Approach**

Dementia is an umbrella term used to describe a range of symptoms that affect cognition, functional abilities, and psychosocial well-being. It can be classified as an acquired geriatric syndrome due to its complexity and need for multimodal management [29]. A complete description of all types of dementia is beyond the scope of this article, however, for a more in-depth review, authors encourage readers to refer to Judge and Dawson [30], Gaugler, James, Johnson, Reimer, Solis, Weuve, Buckley and Hohman [31], Dawson, Beato and McCarthy [32], which each provide more information regarding the various types of dementia. To meet the diagnostic criteria for all-cause dementia, one must present with cognitive, behavioral, or neuropsychiatric symptoms that 1) interfere with function at work or usual activities; 2) represent decline in function or performance; 3) cannot be explained by delirium or major psychiatric disorder; 4) is detected through a combination of subjective and objective measures; and 5) that involves at least 2 domains [33].

Although varying in etiology and symptom presentation, the key cognitive processes impacted are similar across the many different types of dementias. The primary cognitive symptoms of the most common forms of dementia include difficulties in short-term memory, complex attentional processes (i.e., divided and alternating attention), orientation, executive functioning (i.e., decision-making, problem solving, judgment, reasoning, abstract thought), aspects of language production and comprehension, and visual-spatial processing [30, 31]. It is important to note not all of these cognitive processes decline at the same rate or the same way in each patient. Additionally, there are several cognitive processes that remain relatively intact throughout the course of the illness, such as procedural memory [34-36], focused attention [37-39], simple spatial orientation [40], and aspects of language (see Table 1) [41].

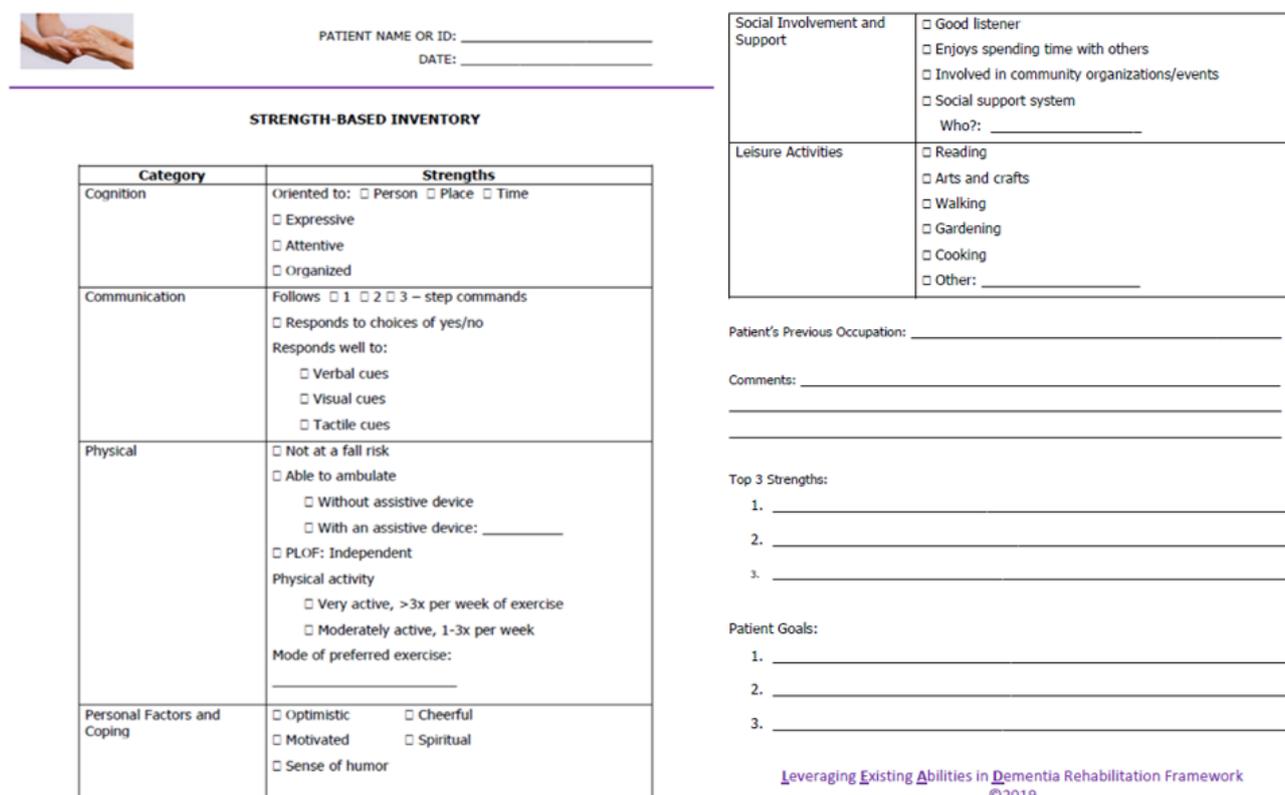
**Table 1** General Impact of Dementia on Cognitive Processes.

	Cognitive Process	Example(s) of Activity
Spared (relatively)	Simple attention	Focused attention on a single task/activity; watching TV
	Implicit learning	Unintentional learning of information or a skill through repeated exposure and practice; learning the words to a song playing on the radio
	Semantic memory	General world knowledge; vocabulary; math skills
	Procedural memory	Getting out of a chair; playing an instrument; long-time leisure activities; any motor-based activity
	Reading	Reading and understanding simple passages, sentences, or single words; reading signs such as a bathroom or exit sign
	Language (simple)	Responding to “yes/no” question; verbalizing wants or needs
	Executive function (simple)	Deciding between 2 simple items for dinner
Impacted	Orientation	Knowing the date or time
	Short-term memory	Remembering a phone number before dialing
	Working memory	Organizing a list in your head; completing multi-step tasks, such as balancing a checkbook
	Explicit learning	Learning a new phone number or rules to a new game
	Episodic memory	Remembering a recent conversation or recent events
	Language (complex)	Having a conversation with someone about upcoming events
	Executive function (complex)	Problem-solving through a difficult problem such as driving in a new city or making decisions among multiple options

Associated difficulties with function (e.g., activities of daily living, mobility, communication) can be described in a hierarchical manner being closely related to cognitive declines with more complex tasks being the most difficult due to higher levels of cognition needed [42, 43]. Just as with the cognitive domain, not all individuals present with the same symptoms, and many have several functional strengths available to them. Individuals with dementia also may experience neuropsychiatric symptoms as well as changes in their behaviors, emotions, personality, and affect.

Examples include agitation, sleep-wake disturbances, hallucinations, delusions, disinhibition [44], frustration, embarrassment, apathy, social withdrawal, loss of self, depression, and anxiety [44]. Individuals typically retain key elements of their personality, emotions, and affect that may be useful when implementing therapy, such as their sense of humor or agreeableness. Therapists can identify these remaining attributes as strengths and exploit them during the patient’s course of treatment, while simultaneously compensating or buffering as needed against the cognitive, functional, and psychosocial losses experienced by the individual.

As part of the LEAD™ framework, rehabilitation professionals are encouraged to use the Strength-Based Inventory (Figure 1) during their evaluation to identify these current strengths and abilities along with key areas of psychosocial well-being and support. Results of the Strength-Based Inventory allow the rehabilitation professional to best identify appropriate treatment strategies within the LEAD™ framework that capitalize on the identified strengths. Implementation of evidence-based strategies and techniques that either compensate or facilitate cognitive processes for PLWDs can assist the therapist in developing a more positive rapport with the individual and lead to a more successful treatment. Table 2 outlines each tenet of the Strength-Based Approach and how the specific tenet is operationalized within the LEAD™ framework for rehabilitation professionals across cognitive, functional, and psychosocial well-being domains. Treatment strategies and facilitators will be described in three key areas: communication, cognition, and coping.



The form includes a header for patient information, a main table for the Strength-Based Inventory, and a section for social involvement and leisure activities. The main table is structured as follows:

Category	Strengths
Cognition	Oriented to: <input type="checkbox"/> Person <input type="checkbox"/> Place <input type="checkbox"/> Time <input type="checkbox"/> Expressive <input type="checkbox"/> Attentive <input type="checkbox"/> Organized
Communication	Follows <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 – step commands <input type="checkbox"/> Responds to choices of yes/no Responds well to: <input type="checkbox"/> Verbal cues <input type="checkbox"/> Visual cues <input type="checkbox"/> Tactile cues
Physical	<input type="checkbox"/> Not at a fall risk <input type="checkbox"/> Able to ambulate <input type="checkbox"/> Without assistive device <input type="checkbox"/> With an assistive device: _____ <input type="checkbox"/> PLOF: Independent Physical activity <input type="checkbox"/> Very active, >3x per week of exercise <input type="checkbox"/> Moderately active, 1-3x per week Mode of preferred exercise: _____
Personal Factors and Coping	<input type="checkbox"/> Optimistic <input type="checkbox"/> Cheerful <input type="checkbox"/> Motivated <input type="checkbox"/> Spiritual <input type="checkbox"/> Sense of humor

Additional form sections include:

- Social Involvement and Support:**  Good listener,  Enjoys spending time with others,  Involved in community organizations/events,  Social support system (Who?: \_\_\_\_\_)
- Leisure Activities:**  Reading,  Arts and crafts,  Walking,  Gardening,  Cooking,  Other: \_\_\_\_\_
- Patient's Previous Occupation:** \_\_\_\_\_
- Comments:** \_\_\_\_\_
- Top 3 Strengths:** 1. \_\_\_\_\_, 2. \_\_\_\_\_, 3. \_\_\_\_\_
- Patient Goals:** 1. \_\_\_\_\_, 2. \_\_\_\_\_, 3. \_\_\_\_\_

Footer: Leveraging Existing Abilities in Dementia Rehabilitation Framework ©2019

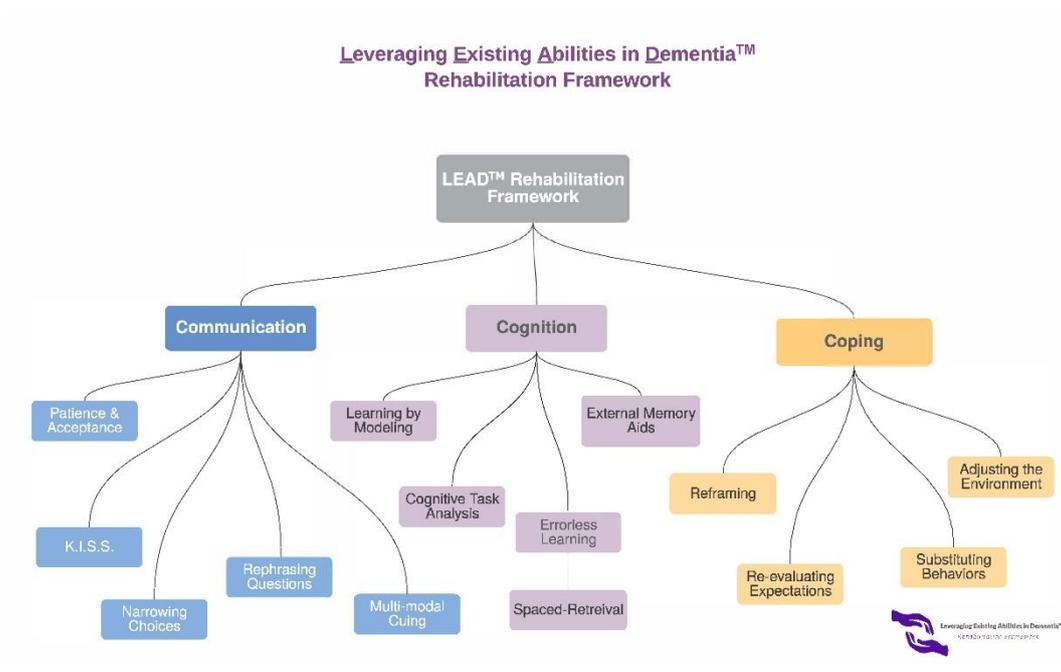
**Figure 1** Strength-Based Inventory. During their initial assessment, rehabilitation professionals can use this inventory to identify current strengths and abilities to best identify appropriate treatment strategies. note. PLOF = prior level of function.

**Table 2** Central Tenets of the Strength-Based Approach.

Tenet	Description	Example
1. Identifying strengths and abilities rather than deficits and limitations	<ul style="list-style-type: none"> <li>Developing treatment plans for PLWDs that capitalize on their remaining strengths</li> <li>Review multiple domains including cognition, communication, physical function, personality and coping, social involvement and support, and leisure activities</li> </ul>	If the patient loves gardening and is doing this at home, therapist could incorporate gardening activities into therapy sessions.
2. Including individuals as active rather than passive participants in treatment process	<ul style="list-style-type: none"> <li>Attending to the personhood of the individual, rather than reacting to the diagnosis of dementia is necessary for active participation</li> <li>Interact with PLWD through meaningful engagement to identify and support interests, preferences, and goals of the individual</li> </ul>	Allow the individual to choose from a selection of activities
3. Emphasizing current possibilities and options rather than past events and performance	<ul style="list-style-type: none"> <li>Encourage highest level of performance at current capacity with appropriate modifications of an activity to facilitate success</li> </ul>	Using a sitting stool while gardening rather than squatting to ensure proper balance

### 3. LEAD™ Treatment Facilitators

After completion of the Strength-Based Inventory (Figure 1), therapists should integrate the identified strengths and abilities into a rehabilitation plan of care. Therapists can use various treatment strategies and facilitators that capitalize on remaining strengths of this population to reduce potential barriers to successful delivery of rehabilitation services. Treatment strategies and facilitators of the LEAD™ framework (Figure 2) are organized into three key areas (“the 3 C’s”) which are outlined in the following sections: Communication, Cognition, and Coping (Table 3). These treatment strategies and facilitators integrate tenets from the Strength-Based Approach [20, 21] along with keys concepts from the information processing model [22-24] and have been found successful when used in intervention and treatment with PLWD [12, 20, 26].



**Figure 2** Leveraging Existing Abilities in Dementia™ Rehabilitation Framework.

**Table 3** Treatment Strategies and Facilitators.

LEAD™ Technique/Strategy	Brief Description	
Communication	Patience and Acceptance	Understand communication deficits may be a consequence of the disease process; allow adequate response in presence of delayed processing
	Keep It Short and Simple	Avoid unnecessary details or fillers during directions and conversations
	Narrowing Choices	Asking questions that can be answered in a few words; providing 1, 2, or 3 choices
	Rephrasing Questions	Stating questions that focus on immediate rather than short-term memory
	Multi-modal Cuing	Repeating information verbally or using physical cues to direct attention and cognitive resources
Cognition	Errorless Learning	Using feedback from the task or environment to ensure individuals learn the correct information
	Spaced-retrieval	Method of learning and retaining new information by recalling target information over increasingly longer periods of time
	Learning by Modeling	Therapist demonstrates how to perform an activity while individual observes and then performs themselves
	External Memory Aids	An accessible environmental visual cue in the form of a calendar, sign, label, list, or notebook used to compensate for losses in short-term memory

	Cognitive Task Analysis	Process of breaking down a task into its simplest components, so that each step can be completed more easily
	Validation	Active listening and acknowledgment of a person’s feelings, emotions, or thoughts; not discounting or correcting what someone says
	Reframing	Decide whether issue is a problem; think about issue differently
Coping	Re-evaluating Expectations	Developing reasonable and realistic therapeutic goals for patient’s current level of skill and ability
	Substituting Behaviors	Replace undesirable/inappropriate behavior with mutually exclusive appropriate behavior (e.g., singing in a group for excessive vocalization such as “help me, help me”)
	Adjusting the Environment	Modify environment to correct under- or over-stimulation

### 3.1 Communication

The ability to adapt communication style and use effective communication strategies is essential to build a therapeutic relationship between care provider and the individual. **The approach** of a therapist during each interaction forms the initial impression perceived by the PLWD. Emotional memory, part of procedural memory, is a cognitive domain that remains relatively intact throughout the disease process. For example, a PLWD may not remember a therapist’s name, but they can still form favorable or unfavorable emotional reactions towards the therapist or situation. Clinicians should communicate with the individual at eye level, make eye contact, smile, introduce themselves, and speak in a friendly manner to create a calm environment. It is advantageous for the clinician to devote adequate time in establishing a strong rapport to understand the individuality of the person living with dementia. Engaging the individual in conversation will assist in identify their strengths, personal interests, values, and preferences that can be incorporated into the plan of care. Rehabilitation professionals may draw upon intact long-term memories and experiences to encourage conversation and facilitate a therapeutic connection during each interaction. They should express empathy towards the individual’s emotional needs and attempt to understand the perspective of their reality and how they are experiencing their illness [45].

Variations in communication abilities require **patience and acceptance** from the therapist. Deficits in working memory, attention, and processing speed can result in difficulties with auditory comprehension and following multi-step commands [46]. PLWDs may have difficulties with word finding and/or demonstrate repetitive or perseverative language [46]. Patience from rehabilitation professionals will provide adequate time for the individual to process incoming information and respond as needed. Delayed processing and variations in processing speed may be present and should be recognized. Several communication strategies can be used to compensate for difficulties in language comprehension and expression. To reduce cognitive load, the strategy of **“keeping it short and simple (K.I.S.S)”** keeps communication direct, short, and simple by avoiding unnecessary cues or filler words. For example, during bed mobility training, ask the individual to “sit up in bed” instead of “grab the handrail, roll over on your right side, then push with your hand and forearm to

push yourself up to sitting”. Another technique to reduce cognitive load is **“narrowing choices”**. Avoiding open-ended questions can be useful for facilitating the PLWD to perform decision making tasks while also including them as an active participant. This strategy instead advises the clinician to use questions with yes/no or reduced multiple choice answers. For example, asking “do you want to walk around outside or toss a ball inside?” rather than asking “what do you want to do in therapy today?”. Choices that include leisure activities that are part of an individual’s procedural long-term memory, such as cooking or dancing, as techniques for exercise may engage the individual, provide more enjoyment, and improve treatment adherence. Rehabilitation professionals can compensate for losses in short term memory by **“rephrasing questions”** to the present rather than the past. For example, asking “Do you have pain now?” versus “Did you have pain over the past few days?”. This might allow a therapist or caregiver to track the patient’s answer to understand tolerance or response to an intervention.

Redirection during various tasks may be necessary by using simple verbal, visual, or tactile cues. **“Multi-modal cuing”** may include verbally repeating information with clear, one-to-two step instructions as described previously in K.I.S.S. that are related to a functional task in order to direct cognitive resources. For example, rather than providing multi-step verbal instructions to perform a sit to stand transfer, simply ask the PLWD to “stand up”. Remaining strengths in procedural memory will allow the PLWD to remember how to perform this familiar functional task. Visual cues (e.g., external memory aids) or learning by modeling can be used through demonstration to assist the PLWD in proper task completion. Physical cues may be needed as tactile sensations to redirect the individual towards success of a task. For example, an occupational therapist may physically guide the patient’s arm during a feeding task. The PLWD may initially require all three types of cues to complete a task. For example, during a sit to stand transfer, the therapist might need to tell the patient how to stand, show the patient how to stand, and physically guide the patient through the transfer. However, after several treatment sessions, the PLWD will begin to learn and require less cues to proper completion due to intact procedural memory processes. The rehabilitation professional can use this “fading cue” paradigm to document progress and learning, by gradually reducing the number of cues over time as learning occurs and performance improves.

### **3.2 Cognition**

**Errorless learning (EL)** is one type of cognitive intervention that bypasses conscious reflection of performance and has been found to be a successful learning strategy in this population by capitalizing on the existing strength of implicit memory [47]. Unlike traditional trial and error learning, individuals are not encouraged to guess or problem-solve why an error occurred in the learning process [48]. Instead, EL maximizes exposure to the correct response while inhibiting incorrect responses [48]. This method of learning engages implicit memory processes by having the patient perform the task multiple times without error so it is consolidated without awareness or intention into procedural memory. One specific technique of EL, called **spaced-retrieval (SR)**, is a “method of learning and retaining information by recalling that information over increasingly longer periods of time” (see Figure 3) [49-51]. To determine whether SR would be appropriate, a simple screening process can be followed in which the clinician develops the lead question with response. Upon determination that the PLWD understands the question and response, practice will be implemented beginning with a five-second delay, advancing to 10 seconds, then 20 seconds, and

ending with 30 seconds [52]. Following the screening process, SR involves the therapist providing the individual with the correct answer or sequence of a task through demonstration and verbal instructions and then asking the individual to repeat the answer or perform the task. The task is then performed repeatedly over increasing time intervals. If there is an error in performance at any time, the therapist immediately corrects the error and returns to the last successful time interval. This technique has been successfully used in speech therapy (e.g., name-face recognition) [53], and can be easily translated to other rehabilitative disciplines. For example, physical therapists can use SR to train an individual on safety awareness during a transfer by conditioning the response of pushing up from the chair, rather than reaching for their walker to stand up. The therapist would first provide the question of, “where do you push from when you stand up?” followed by a correct demonstration of the task. The individual would then be asked to say, “I push from my chair” while performing the task correctly. Recently, SR was used to teach PLWDs to independently use their respective walking aids [54]. Occupational therapists may use SR to enable a patient to remember how to use adaptive equipment such as using a sock-aid or shoehorn after a hip replacement while speech-language pathologists may use this technique to teach their patient to tuck their chin before swallowing. It is important that the healthcare team and the individual’s family and/or caregivers frequently communicate about an individual’s learning style and use consistent cues to prevent disruptions in the learning process.

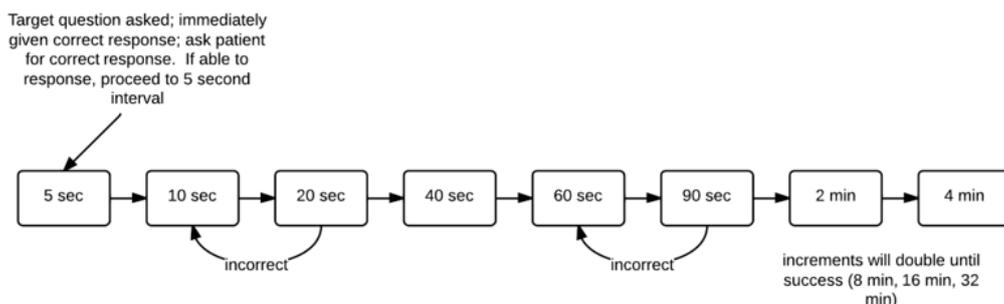
**Initial Training Session:**

1. Begin with prompt question for the target behavior
2. Train the individual to recall the correct answer
3. When retrieval is **successful**, the interval preceding the next recall test is increased
4. If a recall **failure** occurs, the individual is told the correct response and asked to repeat it. The following interval length returns to the last one at which recall was successful

**Subsequent Training Sessions:**

1. Ask the target question
2. If correct, there is **no further training** that session
3. If incorrect, provide immediate correct answer, ask for immediate recall then ask for recall after the amount of time for the **longest successful interval** from the last session
4. If that is answered incorrectly, the correct answer will be provided immediately and a step backwards will be warranted until the correct response is given

\*SUCCESS is achieved when the individual **correctly remembers at the beginning of 3 sessions**



**Figure 3** Spaced Retrieval Technique. One specific technique of EL, called **spaced-retrieval (SR)**, is a “method of learning and retaining information by recalling that information over increasingly longer periods of time” [49-51].

As mentioned above, visual demonstration of a task is embedded within errorless learning to provide visual feedback for the desired response. **Learning by modeling** is a simple cognitive strategy that can be broadly used when teaching a new skill or task. After observing the therapist, the individual should model the therapist through imitation and practice. This strategy leverages the existing strengths of visuospatial processing and procedural memory to provide opportunity for learning without relying on multi-step verbal cues and reduces the associated cognitive load required with explicit processing. Learning by demonstration and use of visual feedback has been found to be more effective than typical trial and error learning with PLWDs [55]. This can be especially useful if the individual has receptive or comprehension language difficulties. Therapists may use this strength by mirroring a motor-based task (e.g. chin tuck for swallowing, brushing teeth, performing a transfer) to provide visual orientation cues to promote success of the individual's performance.

When designing rehabilitative interventions, therapists can exploit cognitive strengths in procedural memory to improve domains of physical performance such as strength and balance. Familiar functional tasks that align with an individual's interests can be structured at the appropriate intensity to produce the desired response [45]. For example, a therapist may identify that an individual with a past time of cooking has standing balance deficits. The therapist may design an intervention that requires the patient to weight shift in standing while performing dynamic reaching outside their base of support into cabinets to gather ingredients for a recipe. Other examples include functional tasks such as weighted sit to stands, walking on uneven outdoor terrain, or reaching for objects at varying heights to simulate grocery shopping. These tasks may be easier to complete for a PLWD than open-chain strengthening exercises with a resistance band or non-purposeful reaching balance tasks, which are likely more unfamiliar and unavailable in long-term memory. By designing familiar tasks that encourage "learning by doing", it is possible for PLWD's to improve their functional abilities and independence with daily activities.

The use of environmental cues such as **external memory aids** capitalizes on remaining strengths in reading and visual processing to facilitate treatment outcomes [56]. Studies have revealed that PLWDs can read simple words and sentences late into the disease process [37, 41]. External memory aids may be used for multiple purposes including enhancing conversation, orientation, and communication of wants and needs; increasing engagement and activity; and modifying difficult behaviors [57]. External memory aids serve as a strategy to prompt memory and provide retrieval cues to compensate for losses in declarative (or verbal-based) memory and can be used in different forms such as of signs, lists, calendars, notebooks, or memory wallets/books. The design of an external memory aid should be bright and bold, legible, clearly detailed, and placed in an accessible location that is easily seen. For example, physical therapists may place a bright sign that reads "please take your cane" on the individual's door to remind them to take their assistive device before leaving the room. Occupational therapists may design a list of written instructions to facilitate a multi-step task such as getting dressed and place the list inside the individual's closet. Labels also can be used to assist with identifying objects in the environment. For example, labels may be placed on dresser drawers or cabinets as an organizational aid. Memory wallets or books provide a way to recall personal information such as addresses, phone numbers, and birthdays. External memory aids also can include pictures with labels or descriptions to assist with recall of past memories and provide face to name recognition for family and friends. In this way, clinicians also are emphasizing

current possibilities to remain independent rather than focusing on past performance of skills and abilities.

Potential barriers to successful rehabilitation outcomes may include frustration or agitation from the PLWD when a task or activity cannot be properly completed as instructed by the therapist. Sometimes, completion of an entire activity may be too difficult or overwhelming. Cognitive task analysis is a strategy that therapists can use to capitalize on remaining abilities of simple focused attention and reduced executive functioning [58]. **Cognitive task analysis** is the process of breaking down a task into its simplest components, so that each step can be completed more easily. In doing so, the therapist can reduce the amount of cognitive processing required. Like motor-based task analysis, which is salient in current rehabilitation practice, cognitive task analysis involves evaluation of each step of the task, identification of the specific step that is most difficult for the individual and applying appropriate modifications to facilitate success. A common example might involve a cooking task that would include the meal planning, recipe reading, and the actual cooking of the meal. Rehabilitation professionals will regularly need to simplify this type of task to improve independence of the patient.

### **3.3 Coping**

Many PLWDs experience a wide range of emotions, behaviors, and neuropsychiatric symptoms that are due to the underlying pathological changes of their illness or due to difficulties in how they are coping with and managing their illness. Recent research has examined these neuropsychiatric symptoms and behaviors within the context of the illness experience [59, 60]. The illness experience incorporates and addresses the subjective aspect of living with dementia, including how PLWD's make meaning of their illness, distress PLWD's may experience due to their dementia symptoms, and how PLWD's cope with and manage their illness. In addition to potential pharmacological management of neuropsychiatric symptoms, these behavioral expressions are important to address and intervene upon as left untreated these behaviors can negatively impede the treatment process.

The following techniques focus on changing the way PLWDs and/or clinicians think about emotions and behaviors. The strategy of **validation** during communication includes acknowledgement of the person's feelings, thoughts, and emotions rather than discounting or correcting what someone says. For example, if the individual expresses that they are upset that they can no longer perform an activity, replying with "that must be difficult for you" rather than, "well, you have Alzheimer's disease, so you shouldn't" is a more appropriate and validating response especially as the PLWD may not remember that they have Alzheimer's disease or why they cannot perform the activity any longer. The technique of validation is an important method for establishing a positive connection with PLWDs along with acknowledging any difficulties and/or emotional distress they may be experiencing. Validation is especially important when an individual expresses a feeling or thought they perceive as important but might not be 'correct'.

#### **3.3.1 Reframing**

**Reframing** is a useful technique when there is not an easy solution or quick fix to an issue. Reframing is a 2-step process where you ask the PLWD whether the particular issue is really a problem and if it is truly an issue than can they think about the issue differently. For example, if an individual is upset about needing therapy, reframing can be used to determine the extent to which

the issue is distressing and how they can think about the issue differently, such as physical therapy will help me maintain my independence. Rehabilitation professionals also can use reframing with themselves when working with PLWDs. For example, a PLWD who is repetitively asking question during a therapy session may leave the therapist feeling frustrated. Using reframing, the therapist can ask themselves if this behavior is really an issue and if it is negatively impacting the effectiveness of the session. If it is distressing but is not overly disruptive, the therapist can change the way they are thinking about this behavior, such as knowing that this is not a purposeful behavior and the PLWD is demonstrating remaining cognitive abilities by seeking answers to their questions. If the repetitive question asking is overly disruptive and not easily reframed, the therapist could then implement spaced-retrieval to facilitate new learning for the PLWD so that they retain the answer to their repetitive question.

### 3.3.2 Re-evaluating Expectations

**Re-evaluating Expectations** is another thinking-based technique that can be used to develop reasonable and realistic therapeutic goals that build upon the PLWD's current skills and abilities. This is especially important given the progressive nature of many dementias. For example, it may not be reasonable and realistic for a PLWD with a hip fracture to return to walking the dog independently; however, it would be reasonable and realistic for the PLWD to walk with his wife who is holding the dog. In this instance, the PLWD still will have the enjoyment of walking with his dog, but the activity has been easily modified to improve feasibility and safety. Additionally, a PLWD may not be able to return to independently being able to prepare large meals for her family at Thanksgiving, but with some set-up and compensatory strategies, she may be able to assist with peeling potatoes, snapping peas, or setting the table. This allows her to still be actively engaged in the activity, but at a reduced cognitive load.

### 3.3.3 Substituting Behaviors

**Substituting behaviors** is a useful technique when the PLWD may be exhibiting an undesirable or inappropriate behavior. The goal is to replace the undesirable or inappropriate behavior with a mutually exclusive desirable or appropriate behavior. For example, disruptive vocalizations could result in an ineffective and difficult therapy session. Substituting behaviors enables the clinician to identify a more suitable behavior that is mutually exclusive to the disruptive vocalization, such as engaging in conversation with the PLWD based on their accessible long-term memories or engaging them in singing.

The last behavioral technique is **adjusting the environment**. Many PLWDs may find the traditional therapeutic setting and the related therapeutic practices either under-stimulating or over-stimulating. Environments that are under- or over-stimulating can result in a range of negative behaviors and hinder progress. For example, a PLWD may find a large treatment room with many individuals and lots of activity going on as overly stimulating. When this happens, it is important to modify the environment to reduce distractions and facilitate cognitive processing. For example, working with the PLWD in a smaller, unoccupied room with minimal objects and noise distractions may be needed. Conversely, a PLWD may be under-stimulated because of lack of engagement and/or purpose while completing a therapeutic task, resulting in boredom, lack of motivation, and/or decreased adherence. It is important that the therapist continually evaluates the interaction

between the PLWD’s skills and abilities and their environment, so that there is balance between the amount of stimulation encountered and the PLWD’s ability to effectively engage with and master their environment.

#### 4. Implementation and Integration of the 3 C’s into Daily Practice

To truly be successful in working with PLWDs, therapists should be able to synthesis and integrate these techniques into their daily practice. This is often the most difficult part of the process; therefore, this section will discuss implementation techniques and overcoming potential implementation barriers to assist the clinician with this patient population.

Most daily interactions with patients will require use of multiple treatment facilitators and techniques. The therapist will be best served by identifying potential strengths through use of the Strength-Based Inventory (Figure 1) during initial and on-going interactions with the PLWD and caregivers. This will provide valuable information to guide plan of care development within the LEAD™ framework via the 3 C’s: Communication, Cognition, and Coping. For example, if the therapist notes that the patient “responds well to visual cues”, then strategies that exploit that strength should be prioritized. Some of these might include learning by modeling, external memory aids, or multi-modal cuing. If a physical strength of “able to ambulate without assistive device” is identified, then the therapist may incorporate various walking activities into the treatment program and use the technique of narrowing choices to allow the patient to identify their preferred activity. More guidance on integrating each principle is outlined in Table 4, which highlights a patient with mild to moderate symptoms, barriers that might be present, and how a rehabilitation professional can use LEAD™ to facilitate success during treatment.

**Table 4** Applying the LEAD™ Framework to Address Potential Barriers in Rehabilitation for an Individual with Mild to Moderate Symptoms.

Potential Barrier	LEAD™ Strategy	Example of Applied Technique
Frustration; Inability to complete activity properly	Keeping It Short and Simple (K.I.S.S.)	Reducing verbal cues during instruction To facilitate standing, use the phrase “stand up” rather than a 5-6 step direction
Decreased motivation to participate; Boredom; Poor adherence	Narrowing Choices	Giving the PLWD choice of 2-3 possible activities rather than asking, “what would you like to do in therapy?”. If possible, choose activities that align with their personal interests
Difficulty understanding instructions to complete an activity	Multi-Modal Cuing	Using physical cues to guide a patient’s hand to the arms of a chair during a transfer Using visual cues (e.g. cones) to display a target that the PLWD can reach during a walking task
Inability to complete activity properly with verbal instructions	Learning by Modeling	Mirroring a dressing task by giving demonstration first, using correct right or left orientation

Poor adherence despite willingness to participate; repetitive questions or demonstration	External Memory Aids	If the individual is forgetting their cane, display a bright sign on their door that says "TAKE YOUR CANE WITH YOU" Placing a visibly accessible sign in their room outlining hip precautions
Poor adherence despite willingness to participate; repetitive questions or demonstration	Spaced-Retrieval	Can be used to assist individual to lock wheelchair brakes, learn how to use a new piece of adaptive equipment, or use compensatory swallowing techniques

#### 4.1 Physical Exercise

**Physical exercise** with PLWDs is another example of the versatility and usefulness of the 3 C's during daily practice. Current exercise science practice guidelines recommend use of functional, progressive exercise when training older adults [61] which is ideal for PLWDs as functional exercise exploits the remaining strength of procedural memory. Treatment strategies and techniques from LEAD™ can be used to facilitate fidelity and adherence to a progressive, moderate-intensity exercise prescription for PLWDs. This approach has been successfully implemented in a home-based, moderate-intensity strength and balance program [26, 62, 63]. Therapists will be more successful by avoiding the use of unfamiliar equipment and exercises, which can be challenging for PLWDs leading to decreased success. For example, if trying to strengthen the quadriceps, a therapist would be much more successful choosing a chair stand or stair climbing exercise rather than an open-chain long-arc activity as the patient regularly stands from a chair or climbs stairs during their lifetime. Another example when developing an exercise program is the avoidance of a conventional fitness center but rather allowing for current leisure activities to be used as mode of exercise can increase adherence to an exercise program.

### 5. Overcoming Barriers to Implementation

When implementing the techniques and strategies outlined in the LEAD™ framework, rehabilitation professionals may encounter some barriers, such as family resistance or interference, a lack of institution or facility support, and reduced cooperation from members of the rehabilitation team. The predominant underlying reason for these barriers is lack of knowledge regarding the abilities of PLWDs and their capacity for rehabilitation through facilitation and compensation. The best approach for the therapist is to look at the situation from the other person's perspective and gather the appropriate evidence to support their treatment approach.

In the case of family caregivers, a therapist would benefit from understanding that the family member has likely been a fierce advocate for their loved one and requires empathy during the episode of care. It is important to allow the family caregiver to interpret the therapist's intentions as positive and helpful rather than threatening. Once that family member realizes that the therapist is on their side, a powerful therapeutic alliance can be formed to assist in overcoming other obstacles. In efforts to overcome resistance or lack of support from the facility and other members of the healthcare team, a rehabilitation professional must be well versed in standards of care and patient's rights. Additionally, some techniques previously mentioned, such as reframing and reevaluation expectations, might be valuable when interacting with families as well. Each

overarching professional organization (American Physical Therapy Association, American Occupational Therapy Association, American Speech and Hearing Association) houses a plethora of information that can assist on this front. Authors encourage therapists to visit these sources. For example, ASHA has a Clinical Practice Guideline titled “Evidence-based Practice for the Use of External Aids as a Memory Compensation Technique” that could be used to defend use of this strategy for PLWDs in a skilled nursing facility or hospital setting.

## **6. Conclusion**

This article introduces the **L**everaging **E**xisting **A**ilities in **D**ementia (LEAD™) Framework for Rehabilitation Professionals using the 3 C's: Communication, Cognition, and Coping. The LEAD™ framework has been developed through the synthesis of the current literature across multiple disciplines to aid rehabilitation professionals (e.g., physical therapists, occupational therapists, speech language pathologists) in approaching service provision with PLWDs in the most beneficial manner. The techniques and strategies also can be used by other members of the interprofessional healthcare team, such as nursing, social work, and psychology to facilitate communication and optimize outcomes for those with dementia. The LEAD™ Framework for Rehabilitation Professionals aims to address the current barriers to care, such as lack of general knowledge and confidence regarding dementia care, how to manage cognitive and emotional behaviors related to dementia, and limited understanding of how to communicate with and engage with these patients [6, 15-17]. The long-term impact of this approach to daily practice could potentially aid in reducing the current healthcare burden associated with AD treatment of \$321 billion, with costs projected to exceed \$1 trillion by 2050 [64]. Hopefully, rehabilitation professionals can facilitate these older adults to age in place rather than require the exponentially high rates of institutionalization when compared to the general population [65]. Rehabilitation professionals play a crucial role in the daily care of PLWDs; therefore, this type of guidance for daily practice is needed for current provision of treatment along with further research to continue advancing the field.

## **Author Contributions**

Dr. Dawson was responsible for the conceptualization of framework along with writing and revising the manuscript. Dr. Trapuzzano was responsible for writing and organizing the manuscript. Dr. Judge was responsible for the conceptualization of the framework along with writing and revising the manuscript.

## **Competing Interests**

The authors have no conflicting or competing interests to declare regarding this manuscript.

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