

# Cognitive Rehabilitation Adherence Failure in Dementia Patients—A Triad of Patient, Caregiver, and Healthcare Challenges

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<sup>1</sup>Rehabilitation Research Center, Aging Research Institute, Tabriz University of Medical Sciences, Tabriz, Iran

<sup>2</sup>Golestan University of Medical Sciences Faculty of Paramedical School, Department of Surgical Technology, Gorgan, Iran

## Abstract

Cognitive impairment and dementia are age-related conditions with extremely high healthcare needs. Cognitive rehabilitation (CR) is a non-pharmacological intervention and an important component of treatment for patients with dementia. Maintaining continuity is a useful concept in dementia care that may confer psychosocial benefits. Non-adherence to non-pharmacological interventions by patients and their caregivers disrupts the efficacy of CR when combined with pharmaceutical interventions. Adherence to CR is hampered by several factors, including psychological and cognitive barriers; caregiver-related challenges; health system and service delivery barriers; barriers related to knowledge, education, and technology; and socioeconomic and cultural factors.

**Keywords:** Cognitive rehabilitation, adherence, dementia patients, perspective

## Introduction

Cognitive impairment and dementia are age-related conditions with extremely high healthcare needs (1,2) and impacts more than 55 million individuals worldwide. There are expected to be 90 million dementia sufferers by 2040 (3).

The main goal of current pharmacological interventions for Alzheimer disease (AD) is to alleviate symptoms rather than alter disease progression. Cognitive training and stimulation are part of the so-called non-pharmacological therapy, which is a significant part of the treatment of dementia patients (4).

Cognitive function is important in adherence behaviours, as evidenced by empirical research on related populations, including older adults with heart failure, which shows that cognitive domain impairments (attention, executive function, and language) independently predict poorer adherence to complex treatment regimens (5).

A specialized treatment strategy, known as cognitive rehabilitation (CR), aims to enhance cognitive abilities affected by brain impairment or injury. Restoring or compensating for lost

cognitive abilities such as memory, attention, executive function, and problem-solving entails thorough assessment, goal-setting, and customized exercises. Both restorative techniques, which concentrate on retraining and enhancing cognitive abilities, and compensatory techniques, which assist people in adjusting to cognitive deficits through the use of tools or alternate techniques, are frequently included in this intervention (6).

To help people better manage their daily tasks and plan their activities, computer-assisted training and assistive technologies, such as Global Positioning System devices and smartphones, are also used. Finding cognitive deficits, establishing quantifiable objectives, offering focused cognitive exercises, practicing skills with progressively harder tasks, and routinely assessing progress are all steps in the process (3).

Since rehabilitation goals are described as “a future state that is desired and/or expected,” rehabilitation can be viewed as a practice focused on the future. The problem of temporality in rehabilitation has been discussed in the literature, which links the patient’s past and present with a potential future state and reveals a variety of potential futures (7).

**Address for Correspondence:** Maryam Chehrehgosha, PhD, Golestan University of Medical Sciences Faculty of Paramedical School, Department of Surgical Technology, Gorgan, Iran

**E-mail:** Chehrehgosha2008@gmail.com **ORCID:** orcid.org/0000-0001-9948-0371

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Understanding and optimizing the benefits of these training programs requires adherence (8). Poor adherence reduces the efficacy of regimens because patients who follow their doctors' and their medications' instructions maximize the benefits of therapies (9). One effective principle for providing dementia care is continuity of care. Continuity maintenance is a helpful idea for dementia care that may have psychosocial advantages (10).

The difficulties faced by dementia patients and their families include non-adherence to non-pharmacological interventions by both the patients and their caregivers, despite research demonstrating the efficacy of CRR in conjunction with pharmaceutical interventions in slowing the disease's progression (11,12). Therefore, understanding the factors that influence patients and caregivers who are reluctant to continue their CRR programs is essential.

Some research suggests that, among patients with non-communicable diseases, medication non-adherence is associated with cultural sensitivity, forgetfulness, drug side effects, lack of access to medications, and patient beliefs. Feelings of despair, disengagement from social networks, and declines in cognitive functioning that may affect memory were other factors (13-16). Lehmann et al. (17) divided barriers into five main categories: factors related to the healthcare system, disease, medication, patient and caregiver factors, and demographic and socioeconomic factors. However, most research focuses on medication adherence rather than on non-medical interventions or rehabilitation. The following is a brief explanation of some reasons why rehabilitation may be discontinued.

Due to a complex interaction of cognitive, psychological, and practical barriers, people with dementia and their caregivers frequently show reluctance toward CR and may discontinue participation in such programs.

Several key elements or categories that can be used to classify the obstacles and contributing factors to nonadherence to CR in patients with dementia. A list of obstacles and elements to improve clarity and flow is provided below:

### Psychological and Cognitive Barriers

**Depression, apathy, and hopelessness:** These factors often accompany dementia. Many patients feel that challenging CR exercises remind them of their deficits, which can increase frustration or a sense of defeat in them. Avoidance and withdrawal are influenced by these "defeatist beliefs," such as the conviction that progress is unattainable. Depression by itself has the potential to be a cause as well as a symptom of disengagement, creating a vicious cycle that deters people from participating in CR (18,19). Grant and Beck (20) describe defeatist beliefs as pessimistic expectations that are based on repeated experiences of cognitive difficulty, such as "I can do this" or "It

will fail anyway" These beliefs reduce motivation to participate in rehabilitation, and so cognitive effort is avoided.

**Disease progression:** Patients with dementia lose cognitive ability, making it harder to engage in CR for an extended period. As functional decline quickens, caregivers may need to rearrange their priorities for care (21,22). Apathy, depression, and agitation are among the behavioural and psychological symptoms that frequently increase with disease progression, further reducing motivation and willingness to engage. These symptoms could make rehabilitation more difficult and unsatisfying, which could cause dissatisfaction and dropout (23).

**Immediate effects of medication:** Despite evidence demonstrating the advantages of both strategies, people with dementia and those who care for them frequently believe that medication is superior to CR for several reasons. Drugs, particularly memantine and cholinesterase inhibitors, are frequently viewed as "active" therapies that target the underlying biological causes of dementia. Patients and caregivers expect pharmacological treatments to yield more rapid and more noticeable outcomes, such as improved memory or symptom stabilization. The widespread availability of drugs and the emphasis placed by healthcare providers on medication as the first line of treatment serve to support this view (21-23). Because of pharmacotherapy-focused reimbursement models, time constraints, or clinical guidelines, doctors frequently emphasize medication. Short or non-existent discussions regarding CR can lead to underutilization and a diminished sense of its significance (12). In contrast to CR programs, which necessitate consistent attendance, mental effort, and caregiver involvement, medications are simpler to administer and require less continuous effort (24,25). A complex combination of perceived immediacy, educational gaps, cognitive and emotional factors, healthcare practices, and practical convenience contributes to the belief in the superiority of medication. It is crucial to balance expectations and improve adherence through enhanced patient and caregiver education on the beneficial role of CR as a supplemental approach.

### Caregiver-Related Challenges

**Caregiver burden and relationship dynamics:** The strain of overseeing day-to-day care and encouraging involvement in CR can ultimately overwhelm caregivers. Caregivers may stop supporting them or may discourage them from continuing if the intervention adds to their time or stress without obvious benefits. Withdrawal may also result from challenging patient-caregiver dynamics and difficulties implementing home-based programs (26).

**Caregiver stress:** Stress among caregivers reduces their ability and motivation to support and facilitate therapy, which, in turn, reduces the likelihood that patients with dementia will adhere to CR over time (27,28). Poorer cognitive function

in patients is associated with high caregiver burden, which further complicates adherence to rehabilitation. This cycle can be managed by providing support to caregivers (29). Research indicates that caregivers who are dealing with psychological distress, family stress, and burnout have a lower quality of life and are less resilient, which has an adverse effect on both their ability to provide effective care and the patient's adherence to rehabilitation (27,30).

### Health System and Service Delivery Barriers

**Resourcing and geographic accessibility of rehabilitation facilities:** Individuals with dementia and their caregivers may face challenges accessing post-diagnostic care. Patients may encounter difficulties starting or regularly attending CR programs due to limited access to specialized rehabilitation facilities, particularly in remote or widely separated locations (31). Residents of capital cities also face this issue due to traffic and long commutes, which make it difficult to access care and services. Public transportation may be crucial in enabling rural or capital city residents to receive medical care while maintaining their preferred place of residence (32). The effectiveness of these interventions depends on regular attendance, which is directly hampered by geographic distance. These patients, especially those who require chronic disease management, are further burdened by challenges in care coordination and disparities in quality among healthcare strata (community, secondary, and tertiary levels). Patients must choose between receiving care at neighbourhood clinics or traveling greater distances to the secondary and tertiary hospitals in the city centre. For patients in rural areas who require care from more specialized hospitals, the inconvenience of time and distance creates further obstacles (33). Since caregivers are typically the ones who bring individuals with dementia to rehabilitation facilities, distance, traffic, and transportation issues make them reluctant to continue rehabilitation sessions and instead rely solely on medication for the older adult with dementia. Geographic and resource constraints (e.g., travel and scheduling) create practical barriers and lower the standard of rehabilitation services, which leads to noncompliance among patients with dementia. To increase participation rates, stakeholders could reduce these obstacles by distributing facilities more widely, allocating more resources, and incorporating home-based or remote technologies.

**Affordability and insurance policy constraints:** CR can be expensive, requiring customized programs, specialized therapists, and, occasionally, long, repeated sessions. Patients may be responsible for increased costs if the cost of their therapy exceeds their insurance benefits, because private insurance coverage varies greatly and frequently imposes copayments, deductibles, and limitations on the number of therapy sessions (34). Mahmood et al. (35) (2023) cite a cost variable as the main reason for non-adherence, along with issues with health literacy

and the absence of a caregiver in their narrative review. An additional review that surveyed older adults' people in low- and middle-income nations focused on the financial obstacles older adults encounter when trying to access rehabilitation, including both direct and indirect costs (36). These review articles address older adults' nonadherence to rehabilitation programs due to financial concerns and barriers. These studies demonstrate how socio-economic status, out-of-pocket costs, and associated expenses, such as lodging and transportation, can lower participation rates among older adult populations.

Rehabilitation services are, unfortunately, not fully covered by private insurers in developing countries; instead, they only cover a portion of medical expenses. This is despite medication therapy and other CR services being crucial for older adults, particularly those who have Alzheimer's. Participants frequently stated that issues with affordability are closely related to insurance, particularly coverage limitations (33). Rehabilitation services in LICs are typically insufficient, underdeveloped, or ill-equipped. Therefore, older adult's people avoid using these services due to high costs or lack of insurance coverage (37). Consistent adherence to CR among patients with dementia is significantly hampered by limited affordability due to patient-borne costs and restrictive insurance policies, such as session caps, cost-sharing requirements, and limited coverage. Policies that increase coverage and lower out-of-pocket costs may contribute to better clinical outcomes and adherence (38,39).

**Pharmacotherapy priority by the healthcare provider:** When the participants were first diagnosed and knew the type of their disease, they reported asking someone else to explain more about the medications and how to take them. Despite the fact that the majority of patients take their medications as directed by medical professionals, some participants reported not taking their medications as directed, feeling let down, and forgetting about it (40). This also applies to rehabilitation therapies; patients frequently forget or arrive late for CR. The majority of seniors consider rehabilitation sessions to be recreational activities and participate at their discretion, not understanding the efficacy of rehabilitation when combined with medication therapy. They are unaware that the effectiveness of rehabilitation depends on the continuity of sessions. CR has been shown in recent meta-analyses to moderately improve occupational performance and quality of life in patients with AD; however, its effects on core cognitive functions (e.g., memory, executive function) are still erratic and weaker (3). Measuring the impact of CR interventions against the backdrop of progressive brain atrophy is challenging, as some studies even show no discernible changes in global cognitive scores after the interventions (21). These gaps indicate that we still do not fully understand CR's broader cognitive efficacy, despite encouraging evidence of its role in enhancing aspects of everyday functioning. An additional issue is the use of technology in CR. Instead of paper-and-pencil

worksheets, CR software is now used because it is more engaging and assesses a broader range of cognitive functions. Technology features that adapt to real-time performance, such as adaptive difficulty, facilitate integration of computerized cognitive training (CCT) and help keep tasks interesting and demanding. Despite the computerization of CCT procedures, the majority of CCT interventions are intended to be delivered in person under the supervision of a qualified expert, such as a therapist or clinician, to guarantee compliance and address technical issues (41). In societies where many older adults lack literacy, and in developing nations where older adults find it difficult to use smartphones, one challenge of adopting new technologies is encouraging older adults to use software in CR sessions and to practice at home with smartphone applications.

### **Knowledge, Education, and Technology Barriers**

**Lack of knowledge about rehabilitation:** Neurodegenerative dementias do not yet have a cure, although certain pharmaceutical and non-pharmacological treatments may help reduce symptoms, delay the course of the illness, and enhance quality of life (42). In order to reduce disability and enhance the quality of life for patients and caregivers, these interventions are designed to preserve function and participation for as long as possible as the disease worsens, rather than to alter the underlying pathophysiological mechanisms (43). Rehabilitation, according to the World Health Organization (WHO), is a comprehensive strategy to maximize function and lessen the perception of disability. Additionally, according to the organization, rehabilitation is essential for people who are functionally impaired due to aging, as well as for those recuperating from illness or injury. The general public would not be familiar with this more recent definition of rehabilitation, and many of the survey respondents would not have previously considered the potential benefits of rehabilitation for age-related or dementia-related disabilities (44). The word “rehabilitation,” according to medical professionals, also suggests that the participant is recuperating from a disease, accident, or injury (such as a stroke). Therefore, even though the programs’ content may be the same, health professionals believed that programs labelled as “rehabilitation” were less suitable for individuals with dementia than programs labelled as “reablement”. Concerns regarding hope and how to carefully strike a balance between providing hope and avoiding false hope were voiced by both health professionals and individuals with dementia (45).

**Misunderstanding of rehabilitation effectiveness:** Medical professionals evaluate effectiveness based on clinically meaningful improvements or maintenance in the patient’s health and independence. They frequently concentrate on whether rehabilitation meets predetermined clinical objectives, like reducing functional decline or enhancing mobility and safety (46,47). The effectiveness of rehabilitation is interpreted

more subjectively and holistically by caregivers, who are frequently family members. They place high importance on noticeable, meaningful improvements in the patient’s mood, daily activities, quality of life, and home environment. Crucially, how rehabilitation affects caregivers’ personal burden, stress, and emotional health—for example, by lowering the need for continual supervision or improving the handling of difficult behaviours—determines how they perceive the program (48). Effectiveness’ in CR is defined as reducing disease progression and patient complications; however, patients and their caregivers define effectiveness as removing all patient complications in two or three sessions. Irrational expectations about the patient’s rehabilitation process result from a conflicting understanding of the concepts of treatment and effectiveness. The patient and his or her caregiver decide not to continue the rehabilitation sessions because they do not believe there will be any noticeable short-term changes in the dementia patient’s behaviour.

### **Socio-Economic and Cultural Factors**

**Low-income and developed countries differences:** When it comes to the mechanisms and justifications for discontinuing CR programs for dementia and related conditions, low-income countries (LICs) and developed countries differ significantly. In developed (high-income) nations, psychological and individual factors, such as patient motivation, depression, cognitive impairments that limit participation, and caregiver burden, are more likely to be responsible for withdrawal than system-level access barriers. Comparatively speaking to LICs, developed healthcare systems typically offer more extensive insurance coverage, which lessens financial strain as a withdrawal factor (12,24). It appears that the most frequent obstacles to rehabilitation adherence in LICs are those related to the health system, finances, cultural beliefs and health literacy, transportation, and practical issues (49,50).

**Cultural beliefs and health literacy:** Cultural norms regarding caregiving and family roles (such as the strong sense of familial duty or “familism” among Latino caregivers) can lead to complicated emotional burdens in addition to influencing willingness and approach to supporting rehabilitation (51,52). Adherence is hampered by low health literacy, which includes a lack of knowledge about dementia, its course, and the justification for treatment. The goals and advantages of CR may be misunderstood by patients and caregivers, who frequently view it as optional or recreational rather than as a vital therapy requiring consistent effort and attendance. Dedication to rehabilitation programs is hampered by this misconception (52,53). Research suggests culturally adapted cognitive therapies (e.g., Cognitive Stimulation Therapy adapted for Māori populations) improve acceptance and effectiveness by respecting cultural values and communication styles (54).

## Conclusion

Cognitive decline, lack of insight, psychological distress (such as depression and defeatist beliefs), perceived lack of benefit, caregiver burden, and logistical challenges are the main causes of reluctance and withdrawal from CR among individuals with dementia and their caregivers. Interventions must address these multifactorial barriers by reducing practical obstacles, supporting caregiver well-being, clearly justifying activities, and customizing CR to each person's needs, thereby improving engagement and adherence. Patients with dementia also face challenges related to the disease course, medication management, affordability, and limited care facilities. Restricting services based on age, symptoms, or severity of impairment creates inequities and ethical dilemmas (55).

How can rehabilitative services be made available to those who need them in settings with limited resources that serve a large population of people with dementia? How can we reduce the aforementioned barriers so that CR therapy is as beneficial to older adults with dementia as medication therapy is?

Although WHO has made commendable efforts toward preserving and enhancing the intrinsic capacities of older adults—introducing six functional domains as care priorities within the framework of the Integrated Care for Older People program—and tailored guidelines can be used to improve adherence to CR in patients with dementia, the enforceability and practical implementation of this program, particularly in LICs, remain uncertain. One possible guarantee for program implementation in developing countries could be requiring the submission of reports on implementation stages.

We may be able to overcome individual barriers to some extent by engaging caregivers in the rehabilitation process, using practical strategies, monitoring progress, and sharing positive feedback. However, in order for more seniors and caregivers to have access to these services, we need the support of health decision-makers.

## Ethics

**Ethics Committee Approval:** Since this study is prospective, this section is not applicable to this type of article.

**Informed Consent:** Not applicable.

## Authorship Contributions

Concept: A.A.Z., M.C., Design: A.A.Z., M.C., Literature Search: A.A.Z., M.C., Writing: A.A.Z., M.C.

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