Individual Cognitive Stimulation in People with Dementia: Good Practices

Silva, Rosa[0000-0002-3947-7098] ✉1,2, Santos-Costa, Paulo[0000-0003-0761-6548]2, Bobrowicz-Campos, Elzbieta[0000-0001-5889-5642]3, Gil, Isabel[0000-0002-5387-8285]2, Cardoso, Daniela[0000-0002-1425-885X]2, Apóstolo, João[0000-0002-3050-4264]2

[1] Health Sciences Research Unit: Nursing, Nursing School of Coimbra, Coimbra, Portugal
[2] Portugal Centre for Evidence-Based Practice: A JBI Centre of Excellence, Nursing School of Coimbra, Coimbra, Portugal
[3] Centre for Psychological Research and Social Intervention at the ISCTE - University Institute of Lisbon (CIS_Iscte), Lisbon, Portugal

✉Corresponding author:
Rosa Carla Gomes da Silva (rosacgsilva@esenfc.pt)

Abstract.

Background: Cognitive stimulation (CS) focuses on the intellectual and social stimulation of people with neurocognitive disorders (NCD or dementia). This intervention is widely disseminated in group settings and may not be accessible or adequate to all people with cognitive impairment. *Making a Difference 3 (MD3)* is an individual CS program in which family (informal) caregivers play the role of home care partners. These individual CS programs should be conducted based on key principles (good practices). **Aim:** To outline a set of good practices that should be adopted during the implementation of individual CS programs by caregivers. **Methodology:** Three main activities were conducted: i) Systematic review of the literature; ii) Translation and cultural adaptation of the MD3 to European Portuguese; iii) Randomized clinical trial with 52 dyads (caregiver and person with dementia) to assess the effectiveness of MD3 and its acceptability and applicability by older adults with dementia and their caregivers. **Results:** Thirteen good practices were outlined based on the values of respect, involvement, dignity, freedom of opinion and choice, understanding, tolerance, and cooperation with older adults with dementia. **Conclusion:** Several good practices were identified for the implementation of individual CS programs by caregivers of older adults with dementia. The healthcare professionals and experts in dementia care and the caregivers considered the recommended practices informative, inclusive, and valuable.

Keywords: Aged, Cognition, Dementia, Cognitive stimulation, Neurocognitive disorders

1 Introduction

Population aging is associated with an increase in the prevalence of major neurocognitive disorders [1, 2], usually referred to in the literature as dementia. There are over 50 million people diagnosed with dementia worldwide, and this number is estimated to rise to 152 million by 2050 [3]. The annual economic impact of dementia is estimated at US$ 1 trillion and is expected to double by 2030 [3].

Older adults with dementia require care that attends to their physical needs but also their psychological and social needs. This paradigm of care aims at increasing their potential for self-care and autonomy, involving and supporting the family, and promoting psychosocial activities [4].

Cognitive Stimulation (CS) is an approach that focuses on intellectual and social stimulation through relevant activities and discussions [5–7]. It aims to improve several domains, such as concentration, thought, memory, and language. There is evidence supporting the effectiveness of CS in improving cognition, mood, well-being, functional activity, quality of life (QoL), and communicational skills, as well as in the consumption of human and economic resources [8–11].

Regardless of the intervention context, the facilitator of CS sessions (group leader/health professional) should be sensitive to the multiple needs of older adults with dementia, take a flexible approach, and adapt the content, order, and structure of the sessions when necessary. Adopting well-defined good practices throughout the various sessions is crucial for the implementation and effectiveness of CS programs [12]. This study aimed to identify a set of good practices to be applied by informal caregivers in individual CS sessions with older adults with dementia.

Dementia is a clinical syndrome caused by neurodegeneration resulting from diseases including Alzheimer's disease, frontotemporal dementia, and Lewy body dementia [1]. It is characterized by changes in specific cognitive domains such as attention, executive function, learning ability, memory, language, motor perception, and social cognition and tends to interfere with individual autonomy [1].

In addition to the loss of cognitive skills, other domains are affected, such as the socialization process, with people with dementia often losing their social functions, such as their family or professional roles. Thus, older adults with dementia can be profoundly affected by a set of limitations usually imposed by third parties, which further affect their learning ability, self-esteem, and relationship skills [13]. In the care relationship, the skills of older adults with dementia are usually not strengthened, and they are deprived of their personality and identity [13]. The dialectics of the socialization process of older adults with dementia has been studied. Kitwood (1990) argued that the interaction with this group reverted into a dynamic similar to the biomedical paradigm, centered on the repercussions of the neuropathological mechanisms of the disease, with a negative impact on care delivery [14]. Therefore, the author introduced the need to share his view among professionals, caregivers, and family members of older adults with dementia, based on the assumption that human beings are deeply affected by the social psychology that surrounds them.

In this theoretical framework, self-esteem is essential for good learning, efficacy, and constructive relationships with others [14]. Conversely, when self-esteem is absent

or deteriorated, the person is incapacitated, falling into a cycle of discouragement and failure [13, 14]. Thus, Kitwood [14] identified ten 'malignant' processes and interactions that tend to depersonalize older adults with dementia: a) treachery, dishonest representation used so that older adults with dementia fulfill the wishes of third parties; b) disempowerment, although the person is able to perform a particular activity with more difficulties or slowly, the activity is performed by another person; c) infantilism, where it is implicitly or explicitly reinforced that older adults with dementia have the skills and the mentality of a child; d) intimidation, where a sense of fear is infused into the older adults with dementia, in some cases being on the receiving end of behaviors such as threatening or even physical aggression; e) labeling, where the diagnosis is associated with decline and consequent progressive disturbance, resulting in a misrepresentation of how the person is treated subsequently; f) stigmatization, similar to the concept of labeling, although it is associated with connotations of social exclusion; g) outpacing, in terms of the rhythm of completion of daily activities, where older adults with dementia are denied their own rhythm, usually slower than before; h) invalidation, when experiences and emotions are forgotten or neglected; i) banishment, when the person is seen by others as somehow intolerable, being physically or psychologically deprived of sustainable human contact; and j) objectification, when older adults with dementia stop being treated as a person and are perceived merely as an empty body.

In this context, health professionals must recognize the specific needs of older adults with dementia and their caregivers, which can vary according to aspects such as family typology, gender, ethnicity, age, religion, and beliefs. For the World Health Organization (WHO, 2015), identifying the most effective interventions for educating, training, and supporting formal and informal caregivers of older adults with dementia is a priority [15]. Thus, the effectiveness of interventions in improving the cognition, social functioning, and QoL of people with dementia should be analyzed, constituting a challenge for current health systems.

In the literature, non-pharmacological interventions emerge as additional strategies for addressing the complexities inherent to the human responses of people with dementia [16]. These non-pharmacological interventions include a set of approaches, such as multisensory stimulation, cognitive rehabilitation, massage, touch, and validation therapy [16, 17]. In this perspective, CS stands out in the context of dementia.

The results suggest that CS is associated with a lower risk of cognitive impairment and should start as soon as possible [18]. CS increases cognitive reserves, protecting against decline, delaying its onset, and causing dependence and inability to self-care [8, 19, 20].

CS is traditionally implemented in group settings, involving the presence of a health professional who conducts scheduled thematic sessions in an institutional context such as hospitals, community rehabilitation units, nursing homes, or day centers [5, 20, 21].

Structured and replicable CS programs have been designed, such as the Making a Difference: An Evidence-Based Group Program to Offer Cognitive Stimulation Therapy (MD)[22] and the Making a Difference 2: An Evidence-Based Group Program to Offer Maintenance Cognitive Stimulation Therapy (MD2)[18]. These programs are designed to assist health professionals and formal caregivers in the context of group CS.

Despite the increasing number of CS groups, these may not be accessible or suitable for all older adults with dementia. Factors such as the lack of these interventions in local institutions, difficulties accessing these groups, comorbidities, mobility restrictions, and reduced interaction in group activities may constitute barriers to the application of these interventions. Thus, the Making a Difference 3 - Individual Cognitive Stimulation Therapy: A manual for caregivers (MD3) was developed to provide other forms of access to CS [23], where informal caregivers play the role of care partners in a home context [6, 23]. However, during the development of the program, it became necessary to outline a set of good practices that guide informal caregivers during individual CS sessions, tailoring the interventions to the reality of older adults with dementia.

Therefore, the following research question was investigated: Which good practices should be adopted by health professionals and informal caregivers of older adults with dementia during the implementation of individual CS programs?

2 Methods

Three main tasks were undertaken: i) A systematic review of the literature (SRL) on the effectiveness of individual CS interventions; ii) Translation and validation of an individual CS program (MD3) for the Portuguese population; iii) A randomized clinical trial (RCT) with 52 dyads (caregiver and older adult) to assess the effectiveness of MD3 and its acceptability and applicability by older adults with dementia and their caregivers.

2.1 Task 1 - Systematic Review on effectiveness of individual CS

A SRL on effectiveness was developed in three stages according to the methodology proposed by the JBI [24,25]. First, using a combination of keywords and index terms, published studies were identified and screened for eligibility by two independent reviewers. Then, after screening the studies against the inclusion criteria, potentially eligible articles were selected and their methodological quality was appraised. Finally, two independent reviewers extracted, assessed, and synthesized data from the included studies [11, 26].

2.2 Task 2 - Translation and Validation of the Making a Difference 3

The MD3 program is an innovative individual CS approach designed to be delivered by caregivers three times a week, in a total of 75 sessions, with the supervision of a health professional [23], and was developed by Yates, Orrell, Phoung, et al. (2015). Its translation and adaptation into European Portuguese followed the phases recommended by the Formative Method for Adapting Psychotherapy (FMAP) [27] and the guidelines for adapting cognitive stimulation [28]. Several activities were carried out, namely: i) initial semi-structured interviews with stakeholders, such as caregivers (*n* =

2), healthcare professionals (n = 3), and academics (n = 3); ii) a panel of experts in dementia care (n = 8); and iii) focus groups with caregivers of older adults with dementia (n = 10) [29].

2.3 Task 3 - Randomized Clinical Trial

The RCT followed the CONSORT (Consolidated Standards of Reporting Trials) guidelines in order to ensure the highest quality of its report. [30] A 12-week two-arm RCT was conducted (individual CS program -MD3 versus control group). The intervention focused on older adults with dementia who lived in their homes (n = 52) and was applied by their caregivers (n = 52). Semi-structured interviews were conducted with four participants who completed the RCT [31,32].

3 Results

In Task 1 (SRL) [11, 26] aimed to identify the most effective individual CS interventions or programs, two studies stood out by the number of positive effects. Quayhagen and colleagues [33] examined the impact of CS and found positive effects on cognitive functioning, particularly memory, attention, and verbal fluency. Similar results were obtained by Davis and associates [34], who found significant post-intervention changes in older adults' memory, attention, and verbal fluency [34]. Both programs were very well structured [33,34]. The cognitive intervention [34] conducted by the caregiver focuses on the attention process and uses different activities, such as multisensory, leisure, and memory-recalling activities. In addition to home-based exercises six days a week, the dyads had weekly contact with healthcare professionals who also performed a one-hour intervention [34]. Healthcare professionals focused on different skills through exercises of face-name association and space retrieval, along with a discussion of older adults' topics of interest [34]. Another intervention [33] focused on memory (assimilations, rehearsal, elaboration, and consolidation), problem-solving, and dialog (social interaction using observational learning and participant modeling) [33]. All participants included in the treatment group received weekly training visits by members of the research team, who trained older adults with dementia and their caregivers in the implementation of CS activities. The caregivers were also asked to demonstrate the techniques learned, consolidating the recently acquired knowledge [33].

Both programs have some aspects in common. They were applied by caregivers six days per week. Formal moments of guidance, training, and supervision were well structured. Moreover, weekly support was provided by healthcare professionals to caregivers [33,34]. Both studies used different strategies to strengthen the bond between dyads and healthcare professionals [33,34]. In one study, healthcare professionals' attendance was weekly, and, during these meetings, new guidelines and support were provided to the caregivers [33]. Moreover, each week, the caregivers were required to fill out a compliance sheet with the time spent on the CS exercises. In the other study, the research team members supervised the home sessions [33]. The caregivers also provided

weekly feedback on successes and challenges faced during the implementation of the program, as well as the time spent on the CS exercises.

The introductory chapter of the MD3 [23,35] highlights 13 key principles that aim to assist the caregiver in the implementation of individual CS sessions. The stakeholders (caregivers, health professionals) valued these principles in all stages of the process (translation and adaptation) and reported that they should be discussed in detail with caregiver during their training and before starting the individual CS sessions [29]. So, caregivers should be aware of the importance of:

- **Mind stimulation**. The main purpose of CS is to activate and engage the mind, offering the possibility of performing stimulating activities.
- **Developing new ideas, thoughts, and associations**. Communication with older adults with dementia tends to focus on past information, which may be "over-rehearsed" and less stimulating. CS programs use techniques that encourage people to use their knowledge to think about things in' new ways.
- **Using orientation in a sensitive manner**. Orientation is an important goal of CS programs, but how older adults with dementia are oriented is crucial. Asking direct questions to the person can be demoralizing. For that reason, orientation should be used subtly and implicitly at the beginning of each session, for example, through a conversation about political parties and important dates.
- **Focusing on opinions, rather than facts, to enhance one's strengths**. If we ask people for their opinions, moving away from the right or wrong dualism inherent to facts, we may get amusing, sad, unusual, controversial, or intriguing answers, but they are not wrong.
- U**sing reminiscence as an aid to the "here" and "now**". Using memories can be useful and fun during CS sessions. Reminiscence can be used to celebrate the family life, personality, career path, hobbies, and achievements of older adults with dementia. Reminiscence can also be useful for orientation, especially in comparing old and new activities.
- **Providing triggers to support memory**. Memory improves when in contact with several senses. So, CS sessions should include activities that simultaneously trigger vision, hearing, smell, taste, and touch.
- **Stimulate language and communication**. There is evidence that communicational skills improve when a person engages in stimulating activities.
- **Stimulate everyday planning ability.** The ability to plan, organize, and sequence, also known as executive functioning skills, is usually impaired in older adults with dementia. In both CS programs, the sessions promote the discussion and implementation of activities in this area to encourage the person to use these tools again.
- **Using a person-centered approach.** In this approach, the person's unique qualities are determined by their life history. The experiences that have shaped their personality and attitudes lead to a variety of abilities, interests, and preferences. Individual CS intends to provide a set of pleasant, showing respect to the person valuing the diversity of their opinions and beliefs, thus allowing each person to be different.

- **Offering a choice of activities.** MD3 sessions offer the person a set of alternative activities if those described do not match their preferences. Offering alternative activities allows older adults with dementia to become involved in the program.
- **Enjoyment and fun.** CS program activities should be provided in a fun and enjoyable learning atmosphere for the person to feel enabled and empowered.
- **Maximizing potential**. There is evidence that older adults with dementia can learn with the right encouragement and support. A crucial aspect is the reconstruction of a person's memory and cognitive skills by allowing them to train these skills. This involves giving the person time to complete the proposed activities at their own pace rather than passively achieving their potential.
- **Strengthening the relationship by spending quality time together.** The individual CS program allows family and friends to be involved in the therapeutic process, focusing on the quality and fun of interacting with older adults with dementia [23,29,32].

During Task 3 (RCT), the research team concluded that caregiver (or, to some extent, dyad) training is essential to the success of the intervention, improving acceptance and adherence to the intervention. Thus, the caregiver (or dyad) pre-program training should adopt the good practices described below [29,31,32].

The first step is to assess the quality of the dyad's relationship (from each member's perspective), as well as their literacy level and motivation to participate in the intervention. Before the implementation of individual CS, the caregiver and the older adult should be provided with: i) a theoretical explanation of the known benefits of CS; ii) the 13 key principles to be implemented during the sessions; iii) the structure and organization of each session; iv) optimal time per session; and v) weekly frequency. Caregivers should be allowed to conduct a mock session in a private environment to identify potential challenges in its application in a home-based setting. The manual for caregivers should be available in printed and digital format, and caregivers should be encouraged to read it to clarify doubts before starting the program.

Then, healthcare professionals should observe/supervise the first sessions conducted by the caregivers to assess their ability to autonomously implement the program based on the key principles outlined in the manual's introductory chapter. After each session, constructive feedback should be given to the caregiver and the older adult. Although early supervision is highly recommended, healthcare professionals should visit the dyad throughout different sessions of these programs, such as the MD3 or another well-structured program translated and adapted to European Portuguese [29].

4 Discussion

Due to population dynamics, citizens should be increasingly involved in care delivery as active care agents [11,29,33]. Thus, training caregivers of older adults with dementia in the implementation of CS interventions is an appropriate strategy with therapeutic benefits.

Making a CS program like the MD3 [23,33] available means providing an opportunity to implement person-centered care and enhance the ability of older adults with dementia to make decisions in partnership with their caregivers. On the other hand, the development of CS activities highlights older adults' life stories, focuses on their tastes and preferences, and creates an opportunity for their personalities to shine. Thus, the healthcare professionals and the caregivers promote the individuality of the older person with dementia as a result of the holistic care and tailored activities offered by well-structured CS programs such as the MD3. One of the concerns with this intervention is the increase in caregiver's burden and the deterioration of their health status and the quality of the dyad's relationship. However, in this study and other studies by Yates [23] and Silva [29], no negative effects were identified for caregivers. On the contrary, Yates and colleagues reported an improvement in the quality of the dyad's relationship [23]. Therefore, healthcare professionals should be aware of the good clinical practices outlined in this study to ensure that individual CS is delivered by the caregiver in a harmonious, engaging, and therapeutic way [29].

Healthcare professionals should assess the incidence of cognitive deterioration in older adults to make an early diagnosis and apply non-pharmacological and pharmacological strategies in the early stages of the disease. At the same time, older adults (when the clinical condition allows it) and their caregivers and/or family members should be aware of the need to play an active role throughout the disease process.

Healthcare professionals, namely nurses, should play a crucial role in training and empowering caregivers and closely supervise and support the dyad during the program, ensuring positive outcomes.

5 Conclusion

Individual CS provided by a caregiver to older adults with dementia is an innovative and useful approach that can be implemented in community settings. The development, implementation, and assessment of individual CS programs should be based on a set of good practices that value the respect, involvement, dignity, freedom of opinion and choice, understanding, tolerance, and cooperation with the older adults with dementia. These good practices can assist and empower caregiver (or dyads) to actively implement individual CS programs, increasing the effectiveness of the intervention.

6 Acknowledgments

The authors acknowledge the support of the Health Sciences Research Unit: Nursing (UICISA: E), hosted by the Nursing School of Coimbra (ESEnfC).

7 Funding

This project received funding from the Foundation for Science and Technology (FCT). This systematic review is also part of the ‘‘Cognitive stimulation in elderly: intervention on cognitive frailty and promotion of self-care’’ project which has received funding from the Nursing School of Coimbra (Portugal).

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