Effectiveness of caregiver-provided cognitive interventions on cognition, social functioning and quality of life among older adults with major neurocognitive disorder: a systematic review protocol

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Review question/objective: The objective of this systematic review is to synthesize the best available evidence on the effectiveness of individual cognitive interventions (CIs) provided by caregivers on cognition, social functioning and quality of life among older adults (≥65 years) with major neurocognitive disorder (NCD).

The review questions are as follows:

What is the best available evidence on the effectiveness of individual CIs provided by caregivers on cognitive domains such as memory, problem-solving and verbal fluency among older adults (≥65 years) with major NCD?

What is the best available evidence regarding the effectiveness of individual CIs provided by caregivers on the social functioning and quality of life among older adults (≥65 years) with major NCD?

Keywords Cognitive intervention; dementia; elderly; individual cognitive intervention; major neurocognitive disorder

Background

The increased elderly population has given rise to a higher prevalence of cognitive deterioration among older people who require care.1 Currently, it is estimated that 46 million people worldwide suffer from a major neurocognitive disorder (NCD), and this number is expected to rise to over 65 million by 2030.1,2 Major NCD is a clinical syndrome caused by neurodegeneration resulting from Alzheimer’s disease, frontotemporal lobar degeneration and Lewy Body disease.1-4 Major NCD is characterized by changes in specific cognitive domains such as complex attention, executive function, learning, memory, language, perceptual-motor and social cognition, and tends to interfere in the person’s autonomy.3,4 The economic impact of major NCD is huge – the total worldwide healthcare cost today is estimated to be US$818 billion.2 This has serious implications for governments and society worldwide.1,2

The effectiveness of interventions on cognition, social functioning and quality of life among older adults with major NCD needs to be analyzed, and it is a challenge for current health systems to provide care to older adults with major NCD.3,6 Older people require care that meets their needs, making the development and implementation of specific interventions a priority. These interventions should aim to increase the person’s self-care potential, promote individual autonomy by adapting to and improving deficits, and promote family support.6,9 Older people with major NCD could benefit from interventions capable of delaying cognitive deterioration in which caregivers and family members act as partners in providing care.5,6

In the literature, non-pharmacological interventions have emerged as an additional option for interventions that focus on the complexities involving the human responses of people with major NCD. Non-pharmacological interventions include a wide range of approaches, such as behavioral intervention, massage and touch, validation, multisensory stimulation, cognitive training, among many others.3 Most of these approaches are considered

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to be effective interventions that should be provided along with pharmacological treatment.\textsuperscript{5,10} Non-pharmacological interventions show positive outcomes among older adults with major NCD.\textsuperscript{5,10,11}

Different terms are used to describe cognition-focused interventions: cognitive stimulation (CS), cognitive rehabilitation and cognitive training interventions.\textsuperscript{12} Clare and Woods defined and described these three approaches which were then used in other publications.\textsuperscript{5,10-13}

In this systematic review, to avoid terminology issues, we use the term cognitive intervention (CI) to refer to these three approaches.\textsuperscript{10-12}

Interventions focused on rehabilitation are targeted at the person’s daily routine (restricted participation) and are developed by a therapist (a healthcare professional) in partnership with the patient and should include the caregiver or family members. They include, for example, using memory aids and errorless learning.\textsuperscript{10-12} Interventions focused on training aim to improve the underlying cognitive process (cognitive impairment). They seek to improve cognitive functions including attention, memory, problem-solving and executive functions. Cognitive training can be provided through individual or group sessions or by family members.\textsuperscript{5,10-12} Cognitive stimulation is a psychological approach that focuses on intellectual and social stimulation through relevant activities and discussions in group or individual sessions.\textsuperscript{5,7,9,10,14-17}

This CI has been associated with stabilization of neuropsychiatric symptoms and improvement of cognitive domains, as well as other non-cognitive outcomes, such as quality of life and social interaction.\textsuperscript{5,11,13,18}

Nowadays, the number of people with major NCD living in their own homes but requiring continuous community care is increasing.\textsuperscript{8,19} Different individual CI programs have been explored as a potential standard intervention to be provided by caregivers.\textsuperscript{6,18,20-26} Individual CI is a one-on-one approach provided by caregivers to older adults who can benefit from it.\textsuperscript{6,11,13,18,20-26}

In this review, caregivers are defined as spouses and other family members or friends who have expressed interest in providing this intervention. The provision of these CI programs by caregivers has been receiving growing attention.\textsuperscript{6,16,20-22} The caregivers who work directly with people with major NCD receive training, guidance and supervision from a therapist (healthcare professional).\textsuperscript{6,21,22} As such, the healthcare unit or stimulation clinic may establish partnerships with caregivers and patients in order to facilitate continuous care (with long-term effects). This intervention program can be implemented in a home setting and in the real-life context.\textsuperscript{6,8,10,16,24}

As pointed by previous studies, this therapeutic solution shows great potential for the future and may be of great practical value in care provision. It may also be applied in specific contexts, such as when patients have restricted mobility or cannot engage in group CS activities, among others.\textsuperscript{20} In addition, the development of individual CIs can reduce pressure on healthcare services and be implemented in a cost-effective way.\textsuperscript{8,16,20,22,24}

According to different studies, the provision of individual CIs by caregivers has shown positive outcomes, including improvement in cognitive domains, such as immediate memory, verbal fluency, problem-solving and orientation.\textsuperscript{18,21-23,25,26} The authors of the studies also reported that individual CIs have contributed to delaying the institutionalization of the care receiver.\textsuperscript{20,22,23} However, results of recent randomized controlled trials (RCTs) using standardized programs have not shown any evidence of improved cognition or quality of life among older adults with major NCD.\textsuperscript{24,27}

Several measurement tools were used to assess these outcomes, such as Alzheimer’s Disease Assessment Scale – Cognitive Subscale, Dementia Rating Scale, Mini-Mental State Examination, Wechsler Memory Scale, Geriatric Coping Schedule, Verbal Fluency Test, Quality of Life in Alzheimer’s Disease Scale (QoL-AD), Dementia Quality of Life Instrument, among others.\textsuperscript{18,20,21,23,26}

Given the uncertainty of the research findings found in the literature and the caregiver’s potential role in CI, a systematic review of these findings would be important for generating evidence to guide clinical practice regarding major NCDs. As shown by previous studies, there is consensus on the effectiveness of CI, to the extent that it can benefit the cognition and quality of life of people with major NCD.\textsuperscript{5,7,9-11,13,28} However, there is insufficient information about the clinical effectiveness of the provision of CI by caregivers,\textsuperscript{18,22} which is necessary to enable clearer understanding of the impact of these interventions.
A preliminary search of the *JBI Database of Systematic Reviews and Implementation Reports*, the Cochrane Database of Systematic Reviews, Prospero, CINAHL, MEDLINE and Epistemonikos, conducted in February and March 2016, revealed that there are currently no systematic reviews on the topic of interest for this systematic review. Recent reviews have indicated that interventions containing non-pharmacological intervention, reality orientation and CS are particularly promising for maintaining the cognitive functioning and quality of life of people with NCD. In this regard, we are interested in knowing what is the best available evidence on the effect of individual CI provided by caregivers on cognitive domains such as memory, problem-solving and verbal fluency among older adults.

**Inclusion criteria**

**Types of participants**
The current review will consider female and male community dwellers (older adults aged ≥65 years) with major NCD.

The review will include studies conducted with participants who have major NCD, regardless of the approach, test, instrument or specific criteria used for diagnosing major NCD, including, but not limited to, the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-4) or fifth edition (DSM-5), the International Classification of Diseases-10 or other relevant cognitive test.

Studies that do not specify methods of clinical diagnosis or that include younger adults (<65 years old) in their samples will be excluded.

**Types of intervention(s)**
The current review will focus on individual CIs provided by caregivers. Studies can include one or more type of CIs (CS, cognitive training and cognitive rehabilitation), and one or more techniques or combinations of techniques, such as games, pictures, mnemonics, visualization, association, cues, use of programs based on manuals or computers programs and others.

Cognitive intervention may be provided with or without supervision but must include at least initial guidance or training provided by the therapist (healthcare professional).

We will consider studies that include any structured CI program in which sessions have no time restriction. These CIs are a one-on-one approach and studies in which CI was not provided by the caregiver at least in four sessions will be excluded.

**Comparator**
The current review will use usual care or other types of interventions as the comparator. Usual care will be defined as the routine treatment received by patients. Other types of interventions will be defined as those provided by the caregiver that does not focus on cognition (e.g. art therapy, multisensory stimulation, etc.) or any non-structured intervention provided by caregivers (e.g. looking at pictures or doing quizzes, etc.).

**Outcomes**

**Primary outcomes:**
- Outcomes related to cognitive domains: memory (immediate and delayed), problem-solving, verbal fluency and social functioning, measured by any validated and reliable instrument, scale or index, such as the Alzheimer’s Disease Assessment Scale – Cognitive Subscale, Dementia Rating Scale, Mini-Mental State Examination, Wechsler Memory Scale, Geriatric Coping Schedule, Verbal Fluency Test.
- Quality of life: measured by any validated and reliable instrument, scale, measurement or index, such as the QoL-AD, the Dementia Quality of Life Instrument.

**Secondary outcomes:**
- Behavior: assessed by any validated and reliable instrument, scale, measurement or index, such as the Behavior Rating Scale of the Clifton Assessment Procedures.
- Mood: assessed by any validated and reliable instrument, scale, measurement or index, such as the Geriatric Depression Scale.
- Activities of daily living (ADL): assessed by any validated and reliable instrument, scale, measurement or index, such as the Katz scale, Lawton Scale, Bristol ADL Scale.

**Types of studies**
The current review will consider experimental study designs, including RCTs, non-RCTs, quasi-experimental and before and after studies. In the absence of research studies, text and opinion papers will be considered for inclusion in this review.
**Search strategy**

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE (via PubMed) and CINAHL will be undertaken, followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Third, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English, Spanish and Portuguese will be considered for inclusion in this review.

The first studies on CI provided by caregivers were published in the mid-1990s; therefore, we will include all studies published from 1995 to 2016.

The databases to be searched include the following:
- PubMed
- CINAHL via EBSCOHost
- Scopus
- Cochrane Central Register of Controlled Trials
- Scielo.

The search for unpublished studies will include the following:
- RCAAP – Repositório Científico de Acesso Aberto de Portugal
- OpenGrey
- Banco de teses da CAPES (www.capes.gov.br).


**Assessment of methodological quality**

Quantitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument from the Joanna Briggs Institute Narrative, Opinion and Text Assessment and Review Instrument (JBI-NOTARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

In the absence of research studies, text and opinion papers selected for retrieval will be assessed by two independent reviewers for authenticity before inclusion in the review using the standardized critical appraisal instrument from the Joanna Briggs Institute Narrative, Opinion and Text Assessment and Review Instrument (JBI-NOTARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

**Data extraction**

Quantitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI-MAStARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. The authors of primary studies will be contacted to provide missing or additional data. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

In the absence of research studies, textual data will be extracted from text and opinion papers included in the review using the standardized data extraction tool from JBI-NOTARI (Appendix II).

**Data synthesis**

Quantitative papers will, where possible, be pooled in statistical meta-analysis using JBI-MAStARI. The meta-analysis will be performed using the random-effects model to allow generalization. However, if less than five studies are included in meta-analysis, and if appropriate the fixed-effects model will be used. All results will be subject to double data entry. Effect sizes expressed as odds ratio (for categorical data) and weighted mean differences or standardized mean differences (for continuous data) and their 95% confidence intervals will be calculated.

Heterogeneity will be assessed statistically using the standard chi-square statistical test. Heterogeneity will be further explored using subgroup analyses based on the different types of interventions (training, rehabilitation and stimulation) and programs of CI included in this review. Where statistical pooling is not possible, the findings will be presented in narrative form including tables and figures to aid in data presentation where appropriate.
In the absence of research studies, text and opinion papers will, where possible, be pooled using JBI-NOTARI. This will involve the aggregation or synthesis of conclusions to generate a set of statements that represent that aggregation, through assembling and categorizing these conclusions on the basis of similarity in meaning. These categories will then be subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that could be used as a basis for evidence-based practice. Where textual pooling is not possible, the conclusions will be presented in narrative form.

Acknowledgements

The authors gratefully acknowledge the support of Health Sciences Research Unit: Nursing (UICISA: E), hosted by the Nursing School of Coimbra (ESEnfC) and Foundation for Science and Technology (FCT).

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References


Appendix I: Appraisal instruments

**MAStARI appraisal instrument**

**JBI Critical Appraisal Checklist for Randomised Control / Pseudo-randomised Trial**

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<th>Question</th>
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<th>No</th>
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<td>1. Was the assignment to treatment groups truly random?</td>
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<td>3. Was allocation to treatment groups concealed from the allocator?</td>
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<td>8. Were outcomes measured in the same way for all groups?</td>
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<td>9. Were outcomes measured in a reliable way?</td>
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Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

________________________________________________________________________

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NOTARI appraisal instrument

JBI Critical Appraisal Checklist for Narrative,
Expert opinion & text

Reviewer ........................................ Date ........................................
Author ........................................ Year ........ Record Number ........

1. Is the source of the opinion clearly identified? □ Yes □ No □ Unclear □ Not Applicable
2. Does the source of the opinion have standing in the field of expertise? □ Yes □ No □ Unclear □ Not Applicable
3. Are the interests of patients/clients the central focus of the opinion? □ Yes □ No □ Unclear □ Not Applicable
4. Is the opinion’s basis in logic/experience clearly argued? □ Yes □ No □ Unclear □ Not Applicable
5. Is the argument developed analytical? □ Yes □ No □ Unclear □ Not Applicable
6. Is there reference to the extant literature/evidence and any incongruity with it logically defended? □ Yes □ No □ Unclear □ Not Applicable
7. Is the opinion supported by peers? □ Yes □ No □ Unclear □ Not Applicable

Overall appraisal: Include □ Exclude □ Seek further info □

Comments (Including reason for exclusion)

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Appendix II: Data extraction instruments

MAStARI data extraction instrument

**JBI Data Extraction Form for Experimental / Observational Studies**

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**Study Method**

- **RCT**
- **Quasi-RCT**
- **Longitudinal**

- **Retrospective**
- **Observational**
- **Other**

**Participants**

- **Setting**

**Sample size**

- **Group A**
- **Group B**

**Interventions**

- **Intervention A**

- **Intervention B**

**Authors Conclusions:**

**Reviewers Conclusions:**
### Study results

#### Dichotomous data

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#### Continuous data

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NOTARI data extraction instrument

JBI Data Extraction for Narrative, Expert opinion & text

Reviewer __________________________, Date __________________________
Author __________________________, Year ______________, Record Number __________

Study Description
Type of Text:

Those Represented:

Stated Allegiance/ Position:

Setting

Geographical

Cultural

Logic of Argument

Data analysis

Authors Conclusions

Reviewers Comments

Data Extraction Complete Yes ☐ No ☐
# SYSTEMATIC REVIEW PROTOCOL

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