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SYSTEMATIC REVIEW PROTOCOL

Experiences of people with progressive memory disorders receiving non-pharmacological interventions: a qualitative systematic review protocol

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ABSTRACT

Objective: This systematic review aims to identify, critically appraise, and synthesize the best available literature on the experiences of people with progressive memory disorders who are involved in non-pharmacological interventions.

Introduction: Some non-pharmacological interventions have been demonstrated to have a significant effect in reducing functional decline in people with progressive memory disorders. Additionally, there is evidence that people with progressive memory disorders have a need for activities tailored to their abilities and interests.

Inclusion criteria: This review will consider studies that describe the experiences of people with progressive memory disorders with non-pharmacological interventions. No limitations regarding care facilities will be made.

Methods: The databases to be searched will include PubMed, CINAHL, Medic, Scopus and PsycARTICLES, as well as MedNar for unpublished studies. Studies published in English, Finnish and Swedish will be considered for inclusion in this review, which will use a three-step search strategy. The papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments and findings will be pooled using meta-aggregation.

Keywords Dementia; experiences; non-pharmacological; nursing; people with memory disorders

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Introduction

With aging of the global population, memory disorders have become a significant public health concern because of their high prevalence, serious consequences of cognitive function and the ability to maintain activities of daily living, and psychosocial consequences for caregivers.¹ Diseases which cause degeneration in memory and other cognitive systems are called progressive memory disorders. Eventually, progressive memory disorders lead to dementia, where a person needs help with all daily functions. Alzheimer's disease (AD) is the most common progressive memory disorder, accounting

for 70% of cases.¹ Other progressive memory disorders include those associated with cerebrovascular disease, Lewy Body disease, dementia associated with Parkinson's disease, and frontotemporal lobar degenerations. The boundaries between subtypes are indistinct and mixed forms often co-exist.¹ In older age groups, particularly, it is common for memory disorders to have a combination of both Alzheimer's disease and cerebrovascular disease characteristics.¹

There is no cure for progressive memory disorders; therefore, the main research interest is in how to promote patient well-being and maintain an optimal quality of life. The Lancet Commission report stresses that quality dementia care is individualized, which highlights the importance of having family-attentive medical, social and supportive care that is re-assessed over time as the individual's condition changes.²

Many non-pharmacological interventions are used for people with memory disorders. These interventions

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are mainly studied with quantitative study designs.^{1,3} Non-pharmacological treatments include a vast array of interventions.⁴ Non-pharmacological interventions are non-intrusive interventions aimed at enhancing the well-being of the individuals that are based on science. They aim to prevent and cure health problems and promote well-being. They can be products, techniques, programs or services which are based on biological and psychological processes identified in scientific research.⁴ Non-pharmacological interventions for behavioral and psychological symptoms of progressive memory disorders can be classified into three categories: individual therapies, targeted interventions and organizational interventions. Individual therapies for people with dementia include, for example, music or exercise activities directed by healthcare providers. Targeted interventions are individual therapies (e.g. reflexology or multimodal cognitive behavioral therapies) aimed at specific symptoms, such as pain. Organizational interventions (e.g. person-centered care skills and communication training or care mapping) involve education for care staff and have been shown to have an influence in managing obtrusive behavior.⁵ In addition to their measurable influence on health, quality of life, behavioral and socioeconomic characteristics, non-pharmacological interventions may have positive effects on experiences.

Two non-pharmacological interventions have been reported to have a significant impact in decreasing decline in physical performance in people with dementia. Exercise and dyadic intervention (therapeutic intervention to engage the person having dementia with their caregiver to maximize quality of life) have been associated with positive effects on activities of daily living.¹ Clarkson *et al.*⁶ have also identified some evidence on the effects of training on activities of daily living for people with dementia, and a review compounding evidence on home support interventions underscores gaps in understanding of the importance of daily living and cognitive training as well as physical activity for people with dementia. Exercise and multi-domain interventions have the effect of decreasing functional decline in people with dementia, therefore healthcare professionals and others close to them should encourage people with dementia to exercise.⁷

Synthesizing qualitative findings can offer insights into how people with memory disorders experience non-pharmacological interventions in their care and demonstrate the most relevant non-pharmacological

interventions methods for people with progressive memory disorders. A recent review provided new evidence from the perspective of people with dementia on their experiences of living in nursing homes. It showed that these individuals were able to describe their experiences and needs – most commonly the need for activities tailored to their abilities and interests.⁸ Likewise, in their review, Lawrence *et al.*⁹ explored how people with dementia experienced psychosocial interventions. The people with dementia felt that they were able to connect with others, make meaningful conversations, express emotions, and show feelings to others. Sharing memories with each other and taking responsibility of a pet brought a sense of purpose to residents' lives.⁹ However, there are no existing reviews that comprehensively explore and synthesize the experiences of people with progressive memory disorders with various types of non-pharmacological interventions. This kind of evidence is beneficial as recommendations for practice in order to increase the use of appropriate and meaningful interventions.

A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews and *JBISRIIR Evidence Synthesis* was conducted, with no current or in-progress systematic reviews on the topic identified.

Review question

What are the experiences of people with memory disorders with non-pharmacological interventions?

Inclusion criteria

Participants

The review will consider studies that include people of any age with progressive memory disorders (including Alzheimer's disease, cerebrovascular disease, Lewy Body disease and frontotemporal lobar degenerations) of any severity. Specific exclusion criteria include Parkinson's disease and alcohol delirium.

Phenomenon of interest

This review will consider studies that describe the experiences of people with progressive memory disorders receiving non-pharmacological interventions, e.g. exercise interventions, music or art therapy, delivered by healthcare or other similar professionals (e.g. music therapist). Interventions delivered by family members, informal caregivers or peers will

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be excluded. No restrictions related to the number of sessions or session durations will be made.

Context

The context will be any setting (e.g. community, nursing home) where these interventions are carried out.

Types of studies

This review will consider studies that focus on qualitative data, including (but not limited to) designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Methods

The proposed systematic review will be conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence.¹⁰

Search strategy

The search strategy will aim to locate both published and unpublished studies, without any time limit. An initial limited search of PubMed and CINAHL was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles and the index terms used to describe the article were used to develop a full search strategy for PubMed (see Appendix I). The search strategy, including all identified keywords and index terms, will be adapted for each included information source. The search will be conducted with an information specialist. The reference lists of all studies selected for critical appraisal will be screened for additional studies. Studies published in English, Finnish and Swedish will be considered for inclusion in this review.

Information sources

The databases to be searched include PubMed (MEDLINE), CINAHL (EBSCO), Medic, Scopus (Elsevier), and PsycARTICLES (ProQuest). The search for unpublished studies will include MedNar.

Study selection

Following the search, all identified citations will be collated and uploaded into RefWorks (ProQuest LLC, Ann Arbor, USA) and duplicates removed. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant

studies will be retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI) (JBI, Adelaide, Australia). The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion between them or with a third reviewer. The results of the search will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram.¹¹

Assessment of methodological quality

Eligible studies will be critically appraised by two independent reviewers for methodological quality using the standard JBI critical appraisal checklist for qualitative research.¹⁰ Authors of papers will be contacted as needed to request missing or additional data for clarification. Any disagreements that arise between the reviewers will be resolved through discussion between them or with a third reviewer, and the results of critical appraisal will be reported in narrative form and in a table. All studies, regardless of the results concerning their methodological quality, will undergo data extraction and synthesis, where possible.

Data extraction

Data will be extracted from studies included in the review by two independent reviewers using the standardized data extraction tool from JBI SUMARI.¹⁰ The extracted data will include specific details about the populations, disease severity, context, culture, geographical location, study methods and phenomena of interest relevant to the review objective. Findings and their illustrations will be extracted and assigned a level of credibility. Any disagreements that arise between the reviewers on credibility will be resolved through discussion between them or with a third reviewer, and authors of papers will be contacted as needed to request missing or additional data. Findings will be extracted based on themes or sub-themes, depending on whether or not they are accompanied by an illustrative quotation directly attributed to a person with a memory disorder. The reviewers will decide

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which of these levels are most representative of the phenomenon of interest.

Data synthesis

Qualitative research findings will, when possible, be pooled using JBI SUMARI with the meta-aggregation approach.¹⁰ This will involve the aggregation or synthesis of findings to generate a set of statements representing that aggregation, which will involve assembling the findings and categorizing them based on similarity in meaning. These categories will then be subjected to synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice by a consensus process between authors. Where textual pooling is not possible, the findings will be presented in narrative form. Information about intervention type and disease severity will be taken account, if available, when categorizing findings.

Assessing confidence in the findings

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings,¹² which will include the major elements of the review and detail how the ConQual score is developed. Included in the Summary of Findings will be the title, population, phenomenon of interest and context for the review; each synthesized finding from the review will then be presented with the type of research informing it, the scores for dependability and credibility, and the overall ConQual score.

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Appendix I: Search strategy

PubMed, May 1, 2020

Records retrieved: 1954

Language limits: English, Finnish, Swedish

(memory dis*[Title/Abstract] OR alzheimer*[Title/Abstract] OR “major neurocognitive disorder”[Title/Abstract] OR dementia[Title/Abstract] OR “cognitive impairment”[Title/Abstract] OR “lewy bod*”[Title/Abstract] OR “memory disorders”[MeSH] OR “dementia”[MeSH] OR “Neurocognitive Disorders”[MeSH] OR “Lewy body disease”[MeSH])

AND

(cognitive stimulation[Title/Abstract] OR cognitive training[Title/Abstract] OR cognitive rehabilitation[Title/Abstract] OR reminiscence therapy[Title/Abstract] OR non-pharmacologic*[Title/Abstract] OR non-pharmacologic*[Title/Abstract] OR nondrug[Title/Abstract] OR non-drug[Title/Abstract] OR psychosocial*[Title/Abstract] OR psychophysical[Title/Abstract] OR psychoeducat*[Title/Abstract] OR “Physical Therapy Modalities”[Mesh] OR “Aromatherapy”[Mesh] OR “Exercise”[Mesh] OR “Acupuncture Therapy”[Mesh] OR “Acupressure”[Mesh] OR aromatherap*[Title/Abstract] OR exercise[Title/Abstract] OR acupuncture[Title/Abstract] OR acupressure[Title/Abstract] OR sensory stimulation[Title/Abstract] OR “Gardening”[Mesh] OR “green care”[Title/Abstract] OR “nature therapy”[Title/Abstract] OR “forest therapy”[Title/Abstract] OR “horticulture”[Title/Abstract] OR “horticultural”[Title/Abstract] OR garden*[Title/Abstract] OR “Gardens”[Mesh] OR “Environment”[Mesh] OR nature[Title/Abstract] OR environment*[Title/Abstract] OR “Art Therapy”[Mesh] OR “Art”[Mesh] OR painting[Title/Abstract] OR drawing[Title/Abstract] OR writing[Title/Abstract] OR sculpting[Title/Abstract] OR “art therapy”[Title/Abstract] OR “Music”[Mesh] OR “Bibliotherapy”[Mesh] OR “Literature”[Mesh] OR art[Title/Abstract] OR music[Title/Abstract] OR poetry[Title/Abstract] OR bibliotherap*[Title/Abstract] OR literature[Title/Abstract] OR “Animal Assisted Therapy”[Mesh] OR “Play Therapy”[Mesh] OR “animal therapy”[Title/Abstract] OR “animal assisted”[Title/Abstract] OR “animal-assisted”[Title/Abstract] OR “toy therapy”[Title/Abstract] OR “play therapy”[Title/Abstract] OR “doll therapy”[Title/Abstract] OR “pet therapy”[Title/Abstract]) OR “robot seal”[Title/Abstract] OR dog*[Title/Abstract]

AND

(“Qualitative Research”[Mesh] OR qualitative[Title/Abstract]) OR phenomenolog*[Title/Abstract] OR ethnograph*[Title/Abstract] OR action research[Title/Abstract])

Medic, May 1, 2020

Records retrieved: 114

lääkkeetön* OR lääkkeettöm* OR fysioterap* OR psykososi* OR psykofy* OR eläinterap* OR leikkiterap* OR robottihyl* OR lemmikkiterap* OR terapiaeläi* OR terapianut* OR taide* OR musiikki* OR kirjallisuus* OR puutarh* OR ympäristö* OR luonto* OR aromaterap* OR liikun* OR akupunkt* OR akupainan* OR stimulaati* OR muistel*

AND

muistihäiriö* OR dementi* OR neurokognitiivi* OR lewy*

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