ISSN: 2634 - 680X

Journal of Clinical Case Studies Reviews & Reports

SCIENTIFIC Research and Community

Review Article

Open Access

Online Psychoeducational Programmes and Multicomponent Exercise for the Patients with Mild Dementia and their Caregivers: A Systematic Review

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ABSTRACT

Background: Dementia is a chronic disorder which, mainly, affects people over 65 years old. It is estimated that it affects over 50.000.000 people around the world. Non- pharmacological strategies can play a vital role in dementia, considering that most of them are low-cost, safe and have no side effects. Psychoeducational programmes aim to inform the informal caregivers about dementia and its progress, and exercise has been showing positive effects in dementia. Their combination has been examined lately in a few studies in terms of enhancing the cognitive functions and quality of life for both patients and caregivers and decrease the unwanted behaviours.

Methods: MEDLINE, PsycINFO, CINAHL and Cochrane Library were searched to identify randomized controlled trials published during 2015-2023.

Results: Four RCTs have been found, which combined psychoeducation with multicomponent training programme. The studies aimed to find if the combination enhanced the cognitive abilities of the patients, and the quality of life for both patients and their caregivers. The studies did not examine the effect of the combination in terms of decreasing the behavioural and psychological symptoms in dementia. The psychoeducation programme aimed to inform the informal caregivers about dementia and what to expect next from the patients, and multicomponent exercise aimed to train the patients in terms of endurance, flexibility, balance and strength.

Conclusions: The combination showed promising results in three out of four studies, however there is a strong need for more studies with better study design and measurements, which will examine if the combination has positive results on decreasing the behavioural symptoms and if the positive results last.

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Received: January 17, 2024; **Accepted:** January 22, 2024; **Published:** January 30, 2024

Abbreviations
AD: Alzheimer's Disease
BPSD: Behavioural and Psychological Symptoms in Dementia
DLB: Lewy Body Dementia
FTD: Frontotemporal Dementia
MMSE: Mini Mental State Examination
PDD: Parkinson's Dementia
PwD: Patients with Dementia
RCT: Randomized Controlled Trial
QoL: Quality of Life
VaD: Cardiovascular Dementia
ZBI: Zarit Burden Interview

Introduction

Dementia is a chronic disorder which, mainly, affects people over 65 years old and is characterised by a declined in various cognition domains (memory, verbal fluency, concentration, attention, social cognition, learning, executive function etc.) [1]. Dementia is an umbrella term for more than 200 brain diseases, however the most common type of dementia is Alzheimer's disease (AD), followed by Vascular Dementia (VaD), Lewy body dementia (DLB), Parkinson's dementia (PDD) and Frontotemporal dementia (FTD) [2]. Dementia is a disorder that impacts almost all daily activities, socialising, and cause emotional and behavioural problems [1]. It is also a disorder which affects the mental and physical health of the unprofessional dementia caregivers [3]. Nowadays, it is estimated that it affects over 50.000.000 people around the world, and the number will increase by 10.000.000 new cases each year. This increase will create a remarkable burden on health and care services, and hence more attention should be paid to optimising services for this disease.

Dementia also causes Behavioural and Psychological Symptoms (BPSD) which are present in almost 90% of PwD, and they lead to caregiver burden, early institutionalisation, low quality of life and mortality [4]. The caregivers, sometimes also called as "second patients", most of the times are informal/ unprofessional caregivers, mostly family members and friends of the patient [5].

Dementia also affects their quality of life, including mentally, physically, emotionally, and financially negative outcomes [4].

The non-pharmacological interventions have gained attention lately, because current pharmacological treatments aim to manage symptomatology, but with severe side effects, such as; diarrhoea, loss of appetite, sleep problems, muscle pain, fatigue, headaches, agitation, vomiting, dizziness etc [6]. Pharmacological solutions aim to maintain the cognitive abilities and manage the BPSD, however cholinesterase inhibitors which are widely used for the treatment of the BPSD have either severe side-effects and/ or uncertain efficacy [7]. Moreover, patients with dementia (PwD) and their caregivers have many needs that it is necessary to be considered comprehensively. Therefore, non-pharmacological strategies can play a vital role in dementia, considering that most of them are low-cost, safe and have no side effects. As non-pharmacological interventions are recommended as first-line treatment, recently dyadic psychosocial interventions have gained attention [8]. These interventions focus on optimising the quality of life for the PwD and his/ her caregiver, as well. There are evidence for promising effects of dyadic psychosocial interventions on cognitive, BPSD, psychosocial outcomes and physical functioning [9].

Furthermore, there is a demand for quality education and training programmes for PwD and their caregivers to help them manage dementia symptoms. Dementia can be a very challenging disease because of its unpredictable nature of the cognitive and its progression [10]. Therefore, the need of education of the dementia caregivers is seen as a priority, globally. Considering the fact that the dementia caregivers are mostly informal caregivers (specifically family members), very often they ask for information and advice on how to manage the BPSD, how to deal with the progression of the disease and how to emotional support their patients and themselves. Psychosocial programmes include both an educational and a therapeutic component in order to be more effective [11]. The educational programmes aim to train the informal caregivers to improve knowledge, skills, communication and confidence [12]. The psychoeducational programmes have been shown to reduce caregivers' burden, decrease depression and stress and built self-confidence and healthy routines [13]. A psychoeducational programme involves a structured and well-oriented didactic knowledge of the progress of dementia, possible daily problems, behavioural strategies, and realistic expectations from the PwD [13]. The psychoeducational programmes aim to transfer knowledge to the general population via lectures, written materials, videos, forums etc. The literature till now has found positive outcomes of the psychoeducational programmes [14]. On the other hand, exercise has beneficial effects on functional status, cardiovascular health, increase of strength, protection against falls, self-efficacy, and reduction of obesity of the PwD [15]. It is also an intervention that can reduce some BPSD, such as agitation, depression, anxiety, wandering, and sleeping problems [15].

The current review aims to find the RCTs which have combined psychoeducational programmes and exercise in order to reduce cognitive decline and improve behavioural symptoms (BPSD) and quality of life in PwD and their caregivers.

Methods

Study Design

In this review we included randomized controlled trials (RCTs) with people with dementia, who were receiving psychoeducational intervention and a multicomponent physical training programme. A three- phase process was used:

Phase 1: We determined the scope of the review question, using the PVO method. P is the study population, and in our review is adults over 60 years old with a diagnosis of dementia), V is the variable, and in our review V stands for the psychopeducational and multicomponent training programme, and O is the outcome, which in our case stands for cognitive functions, BPSD and quality of life of PwD and their caregivers. We determined the inclusion and exclusion criteria based on the review question.

Phase 2: We used the PubMed, Google Scholar, Scopus in order to identify the relevant reviews using key words: dementia, mild dementia, psychoeducation, multicomponent exercise, exercise, online psychoeducation, caregivers.

Phase 3: We identified all the relevant reviews. Two independent reviewers worked separately in order to avoid risk of bias.

A search of databases of Pubmed, PsychINFO, Cochrane, Emboss, Ovid Medline, Emcare and Scopus were conducted in order to identify the inclusion criteria. MeSH keywords was also used. Guidelines of PRISM (Preferred Reporting Items for Systematic Reviews) were followed for the searching process.

Inclusion and Exclusion Criteria

The study is a systematic review. We conducted a search of non-pharmacological interventions for the PwD, especially focused on psychoeducational programmes and multicomponent training programmes. The review is consisted of studies aimed at enhancing the cognitive functions of the patients, reducing the BPSD and enhanced the quality of life (QoL) for patients and their informal caregivers. For the search, we selected studies that 1) were published in English, 2) are RCTs, 3) enrolled patients with dementia or mild dementia, 4) reported outcomes on cognitive functions, BPSD and QoL, 5) included informal caregivers, 6) articles that were published after 2015.

Screening

Two authors screened all abstracts in order to identify relevant papers. Full texts were reviewed by the authors, independently, in order to be screened against the inclusion/ exclusion criteria.

Quality Appraisal and Data Extraction

Using the JBI data extraction tool, the two reviewers extracted data on: authors, year, study aim, study design, sample size, interventions, duration, follow-up period, measurements and outcomes.

Data Synthesis

Due to the heterogeneity of the study design, measurements, outcomes and programme characteristics a quantitative meta-analysis was conducted. A narrative synthesis was undertaken to address evidence. Quantitative and qualitative data were combined into textual description. The transformed data were then synthesised and analysed in order to distinguish outcomes.

Risk of Bias

Risk of bias has been avoided due to JBI tools. To reduce bias further two reviewers worked independently. Any conflict occurred it was solved by discussion. Data extractions were conducted by both the reviewers, who checked each other's work.

Results

Search Results

We identified 4 RCTs that included our criteria. The RCTs varied in length, intensity, activity type and sample size.

Study Characteristics

Studies were conducted all over the world. All studies were RCTs. Study participants were adults with diagnosed dementia, aged 60 years old and up. Most of the patients suffered from AD. The caregivers were exclusively informal caregivers, most of them relatives of the patients and the patients lived at their homes.

Table 1: Characteristics and Details of Included Studies

Author, year	Sample size	Interventions	Duration	Measurements	Outcomes
[16]	44	3 hours duration over the 15-week period (30 sessions in total), 1 h of psychoeducat ion (3 sessions)	2.5 months	30-s chair stand test, 10-m walk test ingle- task and dual-task, Mini Mental State Examination (MMSE), Quality of Life in Alzheimer's Disease	Beneficial results
[17]	111	flexibility, strengthening, balance, and endurance & psychoeducation, a communicatio n skills training, and a pleasant activities training	8 1-hr-long sessions (3 months)	8 Words test, Picture Recognition of the Rivermead Behavioural Memory Test ,Digit Span Test Backward, Key Search Test , Category fluency, Digit Span Test Forward	no effects on the memory and executive functions

Author, year	Sample size	Interventions	Duration	Measurements	Outcomes
[18]	255	(i) education and goalsetting, including ways to compensate for common dementiarelated impairments, (ii) a sequential progression of evidencebased exercises known to improve strength and mobility in older adults, and (iii) behavioral interventions incorporating social support, pleasantevents and the wellestablished A-B-C (activatorbehaviorconsequence) behavioral problemsolving approach to behavior management	2.5 months	30-s chair stand test, 10-m walk test ingle-task and dual-task, Mini Mental State Examination (MMSE), Quality of Life in Alzheimer's Disease	Beneficial results
[17]	111	flexibility, strengthening, balance, and endurance & psychoeducation, a communicatio n skills training, and a pleasant activities training	8 1-hr-long sessions (3 months)	8 Words test, Picture Recognition of the Rivermead Behavioural Memory Test ,Digit Span Test Backward, Key Search Test, Category fluency, Digit Span Test Forward	no effects on the memory and executive functions

Author, year	Sample size	Interventions	Duration	Measurements	Outcomes
[19]	142	Savvy Caregiver programme & aerobic and resistance exercise	6 months	PROMIS Emotional Distress— Depression, PROMIS Emotional Distress— Anxiety, Zarit Burden Interview,Ca regiving Competency Scale	Depression was decreased, psychoeducati on improved anxiety, no changes in caregivers' burden

Outcomes

According to the intervention was group-based with 2 weekly training sessions that lasted 3 hours and the whole programme lasted 15 weeks (30 sessions in total) [16]. Each group consisted of 7-10 participants and all 30 sessions followed this pattern: comprised a 1,5 hour physical exercise programme and the training programme was either combined with 1 hour of CST or 1 hour of psychoeducation. The programme consisted of two groups (14 people with dementia, 13 men, and 13 caregivers) and took place in Copenhagen (total of 44 participants, 89% attended the whole programme). 63.9% of the sample suffered from AD. In terms of measurements, physical functioning was measured using three tests: 30s chair stand test, 10m walk test single and dual task. Cognitive functions was measured using the Mini Mental State Examination (MMSE) test and the quality of life using Quality of Life in Alzheimer's Disease (QoL-AD) scale. Caregivers were offered to participate in the psychoeducation group and to counselling sessions.

The physical exercise took place in a workout room and was led by two specialists (psychotherapists) and included warm-up, cycling, short break and strength exercises. On the other hand, the psychoeducational and counselling programme lasted for 1 hour and addressed the following themes: information on dementia, everyday problems, legal topics and further activities to support the patients. Sessions took place in a group room and was led by a specialist (dementia counsellor). The counselling programme was offered individually. In accordance with the RCT the participants reported beneficial effects from the physical exercise. Even though the training programme left the participants tired, eventually, a lot of them claimed that they got stronger and in better shape. The RCT reports that the participants who were physically active before the programme did not notice a substantial impact, however they recognised that the intervention was a good opportunity to maintain their activity level. However, the RCT reports that the quantitative outcome measures did not show important improvements in the physical and cognitive performance and in quality of life. The qualitative analysis, on the other hand, showed that the participants perceived the programme as an opportunity to engage in a meaningful activity, which was pleasurable and positive. The combination of physical exercise and psychoeducation report positive effects on physical, mental and social health for both patients and their caregivers.

Moreover, the study of had three measurements (baseline and 3 and 6 months follow-up) [17]. The study included 57 patients (N=57) and 54 in comparison group (N=54), which featured a minimal intervention. The study took place in the Netherlands and the patients were living in their homes, without taking serious meds. The intervention group received both the multicomponent and the psychoeducation programme. A personal trainer visited the PwD and their caregivers at their homes for 8 sessions, which lasted 1 hour, during 3 months. The visits of the coach were gradually decreased every month. The programme aimed to enhance flexibility, balance, endurance and strengthening. For the participants who were not active before they were encouraged to complete 30m of active exercise for at least 3 times a week. For the active population the guidance was to complete 30m of active exercise for at least 3 ties a week and preferable on most days. The training programme seems the same with the RCT of [16]. In addition, the goal of psychoeducational programme was to educate the caregivers about dementia and its impact on the PwD and themselves. The programme encouraged the caregivers to engage into beneficial non-pharmacological activities, such as games, music etc. The aim of the psychoeducational programme was to encourage communication between dyads. In terms of measurements, the RCT used The 8 Words Test of the Amsterdam Dementia Screeningtest ADS and the Face and Picture Recognition of the Rivermead Behavioural Memory Test RBMT for memory, the The Digit Span Test Backward is part of the Wechsler Memory Scale–Revised WMS-R, the Key Search Test of the Behavioural Assessment of the Dysexecutive Syndrome BADS and the Category Fluency is a subtest from the Groninger Intelligence Test GIT for executive function and lastly, the The Digit Span Test Forward is part of the WMS-R for attention. 98 people (88%) completed the programme, and 85 (77%) the follow ups [20-25]. 63% of the sample were males suffering from AD (70%). The RCT found some changes in attention but they are not sure if they are a result of the programme. The study also reports no significant differences in executive functions and no effect in memory.

Furthermore, examined both the multicomponent exercise and psychoeducational programme [18]. They also included aerobic and endurance activities, as well as strength training and exercises for balance and flexibility. The psychoeducational programme included topics such as dementia and everyday problems, communication and strategies to improve emotional well-being and reduce the burden of patients' BPSD. The study has a large sample size of 255 participants (N=255). 125 participants (49%) were females and the measurements used were: MMSE, Days exercise ≥ 30 min, past week, SF-36 scores, Revised memory and behavior problem checklist and Quality of Life- AD. The programme lasted for 4 months. The measurements were consistent with those collected as part of the original RDAD RCT: physical activity, exercise days, participants who exercised at least 30m, functional status, physical activity of caregivers, functioning and physical role functioning (SF-36) of PwD and caregivers, QoL-AD and affect of caregivers. The evaluation was taken place by telephonic interviews lasted about 40m. The study reported that the programme was challenging for some participants, however it increased the physical activity, which remained higher at 13 months, which means that the beneficial effects of the exercise remained.

Additionally, conducted a RCT with repeated measures and experimental design and included 3 groups: a) psychoeducation program, b) psychoeducation program and c) home-based exercise and attention control group [19]. The study included Black/ African Americans who have dementia and their relatives, who were visiting the patient at 4 days per week for at least 4 hours of care daily on average. The sample size was finally 153 participants (N=153) who enrolled in the above groups, and the duration period of the study was 6 months. The interventions used was a) psychoeducation program (especially the Savvy Caregiver program, which was adapted for African American caregivers): 2hours of group sessions for 6 times, b) psychoeducation with exercise: the exercise consisted of aerobic and resistance training, and was taken place by an exercise specialist for a minimum of 30min., 5 days per week (aerobic) and for 30m., 2 days per week (resistance training) and c) attention control group: this program included AD educational materials from public sources, and the caregivers attended one group session, which was focused on nutrition education, stretching exercises and flexibility. The RCT used the following measures: The PROMIS emotional distress-depression instrument for measuring the depressive symptoms, the PROMIS emotional distress-anxiety for the anxiety symptoms, the Zarit Burden Interview (ZBI) for measuring caregivers' burden, and the Caregiving Competency Scale for the caregiver mastery. The study found that after the programme the depressive and anxiety symptoms and the mastery improved, and especially the participants who have completed the exercise programme reported further declines in depression and improvements in mastery over time. The study found no significant changes in caregivers' burden scores over time.

Table 2: Demographics of Included Studies

RCT	Males	MMSE (Mean, SD)	Dementia type
[16]	63.9%	23.6 (4.57)	AD 63.9%
[17]	63.1%	21 (5.19)	AD 70.3%

RCT	Males	MMSE (Mean, SD)	Dementia type
[18]	51%	15.6 (7.1)	All types
[19]	14.1%	Not reported	All types

Discussion

This systematic review of 4 studies evaluating the psychoeducational programmes for the dementia caregivers in combination with the multicomponent training programmes provides information on those two non-pharmacological interventions in terms of increasing the cognitive functions of the patients, decreasing their BPSD and improving the general quality of life for both patients and their caregivers. We included only those studies which delivered programmes for both PwD and their caregivers and also measured the two afore- mentioned interventions in combination. Informal family caregivers have been also called "second patients" or "invisible second patients", due to the fact that they experience high rates of mental and physical health issue, as well as social isolation and high rates of anxiety and depression [5]. The programmes were delivered between 2,5-6 months, all over the world. The evidence from the studies suggests that the promising effects of both short and long-term programmes are unquestionable. The studies showed that the psychoeducational programmes when combined with multicomponent exercise had promising outcomes for the PwD and their caregivers.

In terms of duration the Brewster et al., study lasted for 6 months, but report no follow-up, and the shortest study lasted for 2,5 months and had no follow-up, as well [16]. It is surprising that except the RCT of who made a follow- up after 3 and 6 months, no other study had examined the effects of the interventions after a period of time [17]. The sample sized differ a lot, from 44 to 255 participants, and this heterogeneity did not give us the opportunity to conduct a meta-analysis. The intervention programmes had a few similarities: the training programmes used a warm-up and exercises for endurance, strength and flexibility. The education programmes focused on the disease and offered information on daily activities. The multicomponent exercise programme followed a similar structure and duration of the exercises, confirming that the studies have used a protocol in order to apply their interventions. The studies had separated the psychoeducation group and the exercise group and aimed to find effects from the interventions in terms of increasing cognitive functions and quality of life and decreasing the BPSD. However, it is interesting that except the other studies did not use measurements in order to evaluate the efficacy of the training programmes on the PwD and their caregivers [16]. And used a lot of measurements in order to assess the cognitive functions of the patients, however they did not use any measurement in order to evaluate the impact of exercise on the patients [17,19]. Used only MMSE in order to assess the cognitive abilities of the PwD and this seems to be insufficient [16].

The way that the RCTs delivered the interventions is quiet the same. A specialist in exercise and a counsellor specialist in dementia guided the patients and the caregivers. The studies suffer from several limitations. The sample size of was highly educated and most of the participants were women. Furthermore, the study did not collect behaviour and psychological symptoms of dementia [19]. did not find any significant outcome in their RCT, but on the other hand the other 3 studies found positive results [17]. Nevertheless, also reported that if the exercise is of moderate to high intensity and in accordance with participants preferences and needs, there are promising results [17]. One interesting and promising result is that all PwD reported that they felt better after exercising and enjoyed their good shape. Used a large sample size and measured both cognitive functions and physical activity [18].

Future studies should focus on measurements that will evaluate the physical activity levels and the BPSD. This seems to be crucial considering the fact that BPSD affect nearly the 90% of the PwD and most of the times cause distress, caregivers' burden, depression, anxiety and often leads to early institutialization. Moreover, they should use more scales in order to assess the cognitive functions, as MMSE offers a brief evaluation of the cognitive level of the patient, but it does not provide detailed information [26,27].

In conclusion, it seems that the combination of psychoeducation and multicomponent training programme have promising results for the people with mild dementia and their caregivers, because psychoeducation informs the caregivers on matters that are critical and therefore it can reduce their anxiety levels, and at the same time exercise can enhance the quality of life and improve cognitive functions. However, there is a strong need for further research with large sample size, measurements that will also assess the physical activity and improvements and evaluating the impact of the intervention on BPSD, because it is also a crucial matter in dementia, as well.

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