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REVIEW

Systematic review of dyadic psychoeducational programs for persons with dementia and their family caregivers

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Abstract

Aims and Objectives: Synthesising evidence for effects of dyadic psychoeducational support programs on both people with dementia and their caregivers' health and well-being.

Background: There is an increasing need for psychoeducational support programs for people with dementia and their caregivers; therefore, it is important to identify the benefits and practical implications of the programs on the dyads.

Methods: Guided by Joanna Briggs Institute (JBI) methodology, and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework, a systematic search of literature was conducted on dyadic psychoeducational programs published in English between January 2012 and January 2021 from four electronic databases.

Results: Twenty-four studies evaluating 27 psychoeducational programmes were included in this review. Programs varied in activity types, intensity and duration. Outcome effects on people with dementia were grouped into seven categories: quality of life, cognitive function, psychological and mental health, physical health, changed behaviours, communication and relationship, institutionalisation or mortality. Outcome effects on caregivers were grouped into six: psychological and mental health, quality of life, impact of caregiving, communication and relationship, physical health, and competency. Dyadic psychoeducational programs which were goal oriented and tailored to address individual needs had consistent benefits on various aspects of health and quality of life for the dyads.

Conclusions: Multicomponent psychoeducational support programs combined with addressing individual needs, identifying goals and providing support to attain specific outcomes are recommended. Given the progressive deterioration of people with dementia, and the increased needs for homecare by family members, delivering long-term, support programs are recommended to maintain the positive effects on the dyads.

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Relevance to Clinical Practice: The findings contribute to dementia-care provision and policy making and inform the development of person-centred interventions and governance.

Patient or Public Contribution: This systematic review was a part of a larger service evaluation project which involved a dementia consumer advisory group.

KEYWORDS

caregivers, dementia, dyadic, psychoeducation support program, systematic review

1 | BACKGROUND

Dementia is a major public health concern with serious physical and emotional consequences not only for the people with dementia, but also for their family caregivers. It also places a high financial burden upon the healthcare system. People with dementia experience mental and behavioural changes often combining mood disorders, depression, agitation, sleep disturbances, anxiety, psychosis, apathy dysphoria, hallucinations and delusions (Lyketsos et al., 2000). There were about 50 million people living with dementia in 2018 worldwide, and this number is expected to increase to 152 million by 2050 (Patterson, 2018). The global estimated lifetime cost of caring for a person with dementia was about US\$1 trillion annually, which is projected to double by 2030 (Patterson, 2018).

There is limited evidence of the effectiveness and safety of pharmacological treatments for dementia (Dyer et al., 2018; Ijaopo, 2017). As such, non-pharmacological psychosocial interventions are recommended as first-line treatment for behavioural and psychological symptoms of dementia (Dyer et al., 2016; Vernooij-Dassen et al., 2021). In recent years, non-pharmacological psychosocial interventions have gained greater attention to optimising quality of life for both people with dementia and their family caregivers (Brodaty & Arasaratnam, 2012; Wiegelmann et al., 2021). Dyadic psychosocial interventions which focus on both people with dementia and family caregivers are viewed as maintaining person-and-family-centred care (Whitlatch & Orsulic-Jeras, 2018). Evidence for positive effects of dyadic psychosocial interventions on cognitive, physical functioning, psychosocial outcomes for people with dementia and caregivers has been published (Bourne et al., 2020; Whitlatch & Orsulic-Jeras, 2018).

There is an increasing need for quality education, training and support programs for people with dementia and their caregivers to help them manage living with dementia (Hughes et al., 2014; Whitlatch & Orsulic-Jeras, 2018). People with dementia and family caregivers are often challenged by the unpredictable nature of the condition and its progression. Internationally, the need for effective dementia education, knowledge, training and support for caregivers is seen as a priority (Doyle, 2009; Greaves & Jolley, 2010). Family caregivers often ask for information and advice on how to manage the behavioural symptoms of their loved ones with dementia, about the progression of the condition, emotional support and coordination of care (Peeters et al., 2010). Psychosocial programs are strongly recommended to include both an educational and a

What does this paper contribute to the wider global clinical community?

- There is an increasing need for quality education, training and support programs for people with dementia and their caregivers to help them manage living with dementia.
- Dyadic multicomponent psychoeducational support programs targeted and tailored to address individual needs identifying knowledge, skills, goals and provided support services to attain specific outcomes appeared to be more beneficial than programs which were not goal oriented and tailored to individual needs.
- Delivering interventions for a long-term period can be beneficial to maintain the positive effects on the dyads.

therapeutic component to be most effective (Dickinson et al., 2017). Effectiveness of dementia education and training alone to improve knowledge, attitude, confidence and communication of professional caregivers have been reported (Eggenberger et al., 2013; Parveen et al., 2021). However, there is a lack of evidence whether educational interventions improve the behavioural and psychological symptoms of people with dementia, and meet the needs of caregivers. In a systematic review, Vandepitte et al. (2016) examined the effectiveness of different supportive programs on the well-being of the family caregivers of dementia. The authors found that psychoeducational interventions had positive outcomes for caregivers and people with dementia; however, they did not focus on dyadic programs in particular. It is important to identify the evidence of benefits and practical implications of dyadic psychoeducational support programs on people with dementia and their family caregivers for developing effective dementia interventions for the dyads.

The aim of the current review is to address the following two questions: (1) what psychoeducational support programs are available for both people with dementia and their family caregivers; and (2) what impact do dyadic psychoeducational support programs have on both people with dementia and their family caregivers' health and well-being. Psychoeducational approach provides a framework for helping people gain knowledge and understanding, and develop skills to cope with their disease-related problems (Vandepitte et al., 2016). Psychoeducational interventions for dementia involve a structured

program and cover a broad range of activities including information and knowledge of the condition, care organisation, self-care, counselling, emotional effects, cognitive restructuring techniques, problem-solving techniques, coping, communication, skill buildings activities, lectures, group discussion and written materials (Sørensen et al., 2006; Vandepitte et al., 2016). Various classifications of interventions are seen in the current literature due to overlap of common components across interventions (Sørensen et al., 2006). For this reason, articles considered for inclusion in this review, where psychoeducational components were combined with any other psychosocial activities in the intervention evaluated.

2 | METHODS

2.1 | Study design

This review was guided by the Joanna Briggs Institute (JBI) methodology for conducting mixed methods systematic reviews to include diverse forms of evidence from different types of research (Pearson et al., 2014; Stern et al., 2020), and it followed the internationally recognised Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework for reporting (Moher et al., 2009). Mixed methods approach was deemed appropriate for this review because, by pooling evidence of quantitative and qualitative inquiries, this study maximises the findings and thus has the ability to inform policy and practice (Pearson et al., 2014). This review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) prior to commencing of database search.

2.2 | Search terms and search strategies, and data source

An initial search of MEDLINE-EBSCOhost was performed to identify key words and Medical Subject Headings (MeSH) terms related to people with dementia and family caregivers, psychosocial programs, and outcomes on health and well-beings. A comprehensive search terms was then developed using a combination of indexing terms, MeSH, truncations, Boolean operators and key words. The search strategy was tailored to each of the four databases MEDLINE-EBSCOhost, CINAHL, PsycINFO and Embase to account for variations in subject/index terms. The reference lists of included articles were further reviewed for potentially relevant studies. Recent citations of the included studies were also reviewed for inclusion. An example of key and MeSH terms used for MEDLINE-EBSCOhost search as shown below.

(Alzheimer* OR dement* OR ([MH "Alzheimer Disease"]) OR ([MH "Dementia+"])) AND (caregiv* OR family OR relatives OR ([MH "Caregivers"]) OR ([MH "Family+"])) AND (intervention OR psychosocial OR (social support) OR counselling OR counselling OR (support program) OR training OR ([MH "Psychosocial Support Systems"]) OR ([MH "Counselling"]) OR ([MH "Social Support"]) AND community.

2.3 | Inclusion and exclusion criteria

Studies that evaluated community-based non-pharmacological dyadic psychoeducational support programs for people with dementia and their family caregivers living in the community were considered for inclusion. Studies employed quantitative research methods including experimental or observational, as well as qualitative research methods were assessed for inclusion. Studies that involved psychoeducational support programs in which at least one component had a face-to-face contact between the program facilitator and the participants were included in this review. The programs could target a variety of functional domains including, but not limited to, psychological and behavioural symptoms, quality of life, cognitive function, competency, sleep, independence in activities of daily living, institutionalisation and impact of care giving. Databases were first searched in early 2020 to identify records published between January 2012 and January 2020. The search was updated in 2021 to capture current records up until January 2021.

We intended to capture the research studies conducted in the last 10 years since the commencement of the US National Plan to Address Alzheimer's Disease in 2012 for reducing the burden of Alzheimer's disease and related dementias and to better meet the needs of their caregivers (Khachaturian et al., 2012), as well as the Healthy Brain Initiative by the Centers for Disease Control and Prevention and the Alzheimer's Association to promote strategies to increase awareness and communication about dementia (Batsch & Mittelman, 2015). Consequently, studies published between January 2012 and January 2021 in English and from any geographical location were considered for inclusion in this review. Studies were excluded if the intervention program targeted people with dementia or caregivers alone. Studies conducted in hospitals, nursing homes or institutional programs, pharmacological studies, programs that targeted younger people with dementia were excluded. Conference proceedings and pre-print studies which had no evidence of acceptance by peer-reviewed journal up until January 2021 were also excluded from this review.

2.4 | Screening

All records that identified from the four databases and met the inclusion criteria were exported to a web-based systematic review management RAYYAN. Following removal of duplicate records, two reviewers screened title and abstracts to exclude irrelevant and incomplete records. Full texts of the remaining articles were then screened against the inclusion/exclusion criteria in this systematic review.

2.5 | Quality appraisal and data extraction

Eligible studies were assessed using the JBI standardised critical appraisal checklists: "Checklist for Quasi-Experimental Studies", "Checklist for Randomised Control Trial", "Checklist for Cohort

Studies" and "Checklist for Qualitative Studies" which were developed to measure the feasibility, appropriateness, meaningfulness and effectiveness of healthcare interventions (Pearson et al., 2014; Stern et al., 2020). Using the JBI data extraction tool, two reviewers extracted data on author, year, country, study aim, study design, sample size, program components, program duration, follow-up period, outcomes measured, instruments used to measure outcomes for each program and reported effects on people with dementia and caregivers. All research methods were included, and there was no limitation for program duration.

2.6 | Data synthesis

Characteristics of all studies including country of study, study design and comparator sample group, as well as characteristics of all evaluated psychoeducational programs including program contents and program duration were summarised. Due to the heterogeneity of the study design, program characteristics and measurement of outcomes, a quantitative meta-analysis was considered inappropriate. Instead, a textual narrative synthesis was undertaken to report evidence which address this systematic review aims in a valid and meaningful way. A convergent integrated approach guided data transformation in which quantitative and qualitative data were combined into textual description form described as "qualitised" (Stern et al., 2020). Transformed data were then synthesised and analysed to identify outcomes for people with dementia and their family caregivers.

2.7 | Risk of bias

The JBI critical appraisal tools and PRISMA framework guided the reviewers to conduct quality assessment of included studies (Supplementary File 1) and to assess for risk of bias in each study (Supplementary File 2). To reduce bias and enhance rigour in this systematic review, two reviewers (MD and MG) independently screened and conducted quality appraisal for each study. Studies identified as "maybe" and "conflicts" were assessed by the third reviewer (BOC). Data extractions were also conducted by MD and MG who checked each other's work. All reviewers were involved in data synthesis, and they discussed any discrepancies until a resolution was reached.

3 | RESULTS

3.1 | Search results

The combined searches yielded 4400 records. After removal of duplicates ($n = 1844$), titles and abstracts were screened ($n = 2556$), inclusion and exclusion criteria applied, 26 studies remained for quality appraisal, and 25 articles were considered eligible for this review. Of them, two articles (Prick et al., 2015, 2016) derived from the

same research but results for people with dementia and caregivers were published separately. These two articles were combined into one for analysis. Thus, the total number of studies counted for this review was 24. This total number also included one article which was found when the search was updated. The study selection process is presented in Figure 1.

3.2 | Study characteristics

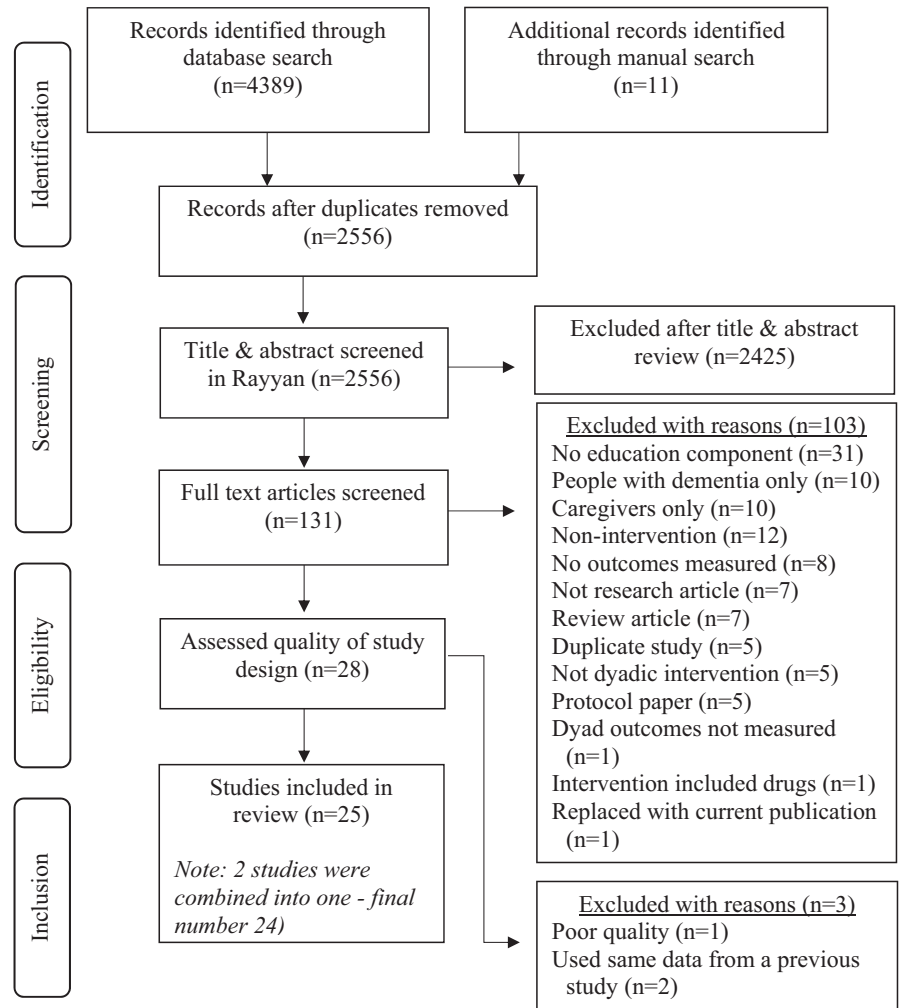
Studies varied in research methods, follow-up period, outcome measurement and instruments used to measure outcomes (Table 1). Studies were conducted in European countries including UK ($n = 13$), United States and Canada ($n = 7$), Australia ($n = 2$), Brazil ($n = 1$) and Hong Kong ($n = 1$). Sixteen studies were randomised control trials, seven were quasi-experimental including pre-post intervention, and one was qualitative involving multiple case studies (Forbes et al., 2018). While most studies had a usual care program available in the community as a control group, some studies examined more than one intervention to compare results. Two studies had separate programs for people with dementia and caregivers and compared individually and in combination against usual care (Charlesworth et al., 2016) or a waitlisted control (Cove et al., 2014). Study participants were adults aged mostly aged 60 years old and up. Caregivers were mainly female (more than 70%) and were in spousal relationship (70%–80%). Other caregivers included offspring, siblings, adult grandchildren and in-law other non-family members.

3.3 | Program characteristics

There were 27 programs evaluated in the 24 included studies. Programs varied in activity types, intensity and duration. Based on length of program delivery, studies are presented under short-term ($n = 12$) and long-term period ($n = 12$) programs. Short-term programs were delivered within a 3-month period (6–14 weeks), and long-term programs were offered for more than 3 months (more than 14 weeks). One program was delivered over 24 months (Koivisto et al., 2016), and another program followed up to 36 months to measure outcomes (Phung et al., 2013). Programs often included a combination of single and group sessions, and comprised multiple components, including information sessions on dementia and support services, exercise training, behavioural training, coping strategies, psychoeducation, cognitive therapy, behavioural therapy, reminiscence therapy, problem solving and counselling.

The programs were mostly delivered face-to-face by trained facilitators or professionals as appropriate in community settings. Some programs combined face-to-face delivery along with telephone counselling and/or follow-up (Kunik et al., 2020; Nordheim et al., 2019; Phung et al., 2013; Stanley et al., 2013; Yu et al., 2019). There were 13 home-based programs found across the studies. Of

FIGURE 1 Article search and selection process using the PRISMA (preferred reporting items for systematic reviews and meta-analysis) framework. This figure represents the article search and selection process of electronic databases and manual search using the PRISMA framework.



them, ten programs were offered at participating dyads' home, in one program, the dyads stayed in a self-contained cottage (Gresham et al., 2018) provided by the study team, and another two had home-visit components (Cornelis et al., 2018; Forbes et al., 2018). Of the 13 home-based programs, seven were short-term (Gresham et al., 2018; Kunik et al., 2020; Nordheim et al., 2019; Prick et al., 2015, 2016; Teri et al., 2020; Williams et al., 2018; Yu et al., 2019), and six were long-term (Cornelis et al., 2018; Forbes et al., 2018; Jeon et al., 2020; Novelli et al., 2018; Phung et al., 2013; Stanley et al., 2013).

3.4 | Outcomes

Findings were synthesised into two major categories: outcome effects on people with dementia and outcomes effects on caregivers. Each synthesis contained sub-categories (Figure 2).

3.4.1 | Outcome effects on people with dementia

The outcome effects on people with dementia reported in the included studies were grouped into seven categories: quality of life

(n = 16), cognitive function (n = 12), psychological and mental health (n = 12), physical health (n = 9), changed behaviours (n = 5), communication and relationship (n = 2), and institutionalisation or mortality (n = 3) (Table 2).

Quality of life outcomes for people with dementia

Two of the 16 studies which measured quality of life reported significant improvements, one (Collins et al., 2018) offered a short-term program in a pre-test/post-test study comprising 12h of sessions on focused psychoeducation, breathing and mindfulness with outcomes measured after completion of the program at six weeks. The other program involved pre-test/post-test study design (Cornelis et al., 2018) and offered 25h of a multicomponent home-based tailored program including counselling, cognitive and behavioural strategies, psychoeducation and goal attainment over 12 months. Six studies which reported heterogeneous effects on quality of life, one of them (Charlesworth et al., 2016) reported significant interaction when two programs were combined; two studies (Dröes et al., 2019; Jeon et al., 2020) showed positive effects, but the effect was not significantly different to the control groups; another two (Novelli et al., 2018; Villars et al., 2021) observed differences between subjective ratings by the dyads; and the other one (Stanley et al., 2013)

TABLE 1 Characteristics and details of included studies and dyadic psychoeducational support programs

| No | Author, year, country and study design | Program description | Sample size and follow-up period | Outcomes measured and instruments used for people with dementia | Outcomes measured and instruments used for caregivers |
|--|--|--|--|---|---|
| <i>Short-term support program—3 months or less</i> | | | | | |
| 1 | Collins et al. (2018), UK. Pre-test/post-test | Compassion-Focused Therapy. 6 × 2 h weekly sessions. Components: psychoeducation, mindfulness, breathing, compassion | 64 dyads. 6 weeks | Anxiety & depression: HADS; respiratory rate: the number of inhalations taken in one minute prior to engagement in the intervention; Quality of life: QoL-AD | Anxiety & depression: HADS; respiratory rate: the number of inhalations taken in one minute being seated, and prior to engagement in the intervention Quality of spouse relationship: QCPR |
| 2 | Cove et al. (2014), UK. RCT | Intervention1: Cognitive Stimulation Therapy (CST) plus Carer Training (CST + CT). 14 × 45 min weekly sessions for people with dementia. 1 × 3 h session and 1 × 1-h session, optional workshop for caregivers. Intervention2: CST only, 14 weekly CST sessions. Component: Individually themed sessions, group discussion, song and exercise for people with dementia. Information on dementia, CST, record keeping of activities, skill development for caregivers | Intervention1 = 21 dyads, Intervention2 = 24 15 weeks | Cognition: MMSE & ADAS-Cog; QoL: QoL-AD; Quality of relationship: QCPR | |
| 3 | Gresham et al. (2018), Australia. Pre-test/Post-test | Going to Stay at Home. 14 sessions in 5 days. Dyads stayed in a cottage. Components: For people with dementia: cognitive stimulation, physical activity, social and domestic activities. For caregivers: psychological support, information, coping strategies, problem solving and future plans | 90 dyads. 6 and 12 months | Anxiety & depression: K-10; Residential care placement; Activities of daily living: IADL and PSMS; QoL: QoL-AD; Neuropsychiatric symptoms: NPI; Agitation: CMAI; Dementia severity: GDS; Cognitive function: MMSE | Impact of caregiving: ZARIT-BI; QoL: OPQoL-Brief; Health status: SF-12; Needs met: Self-report needs met scale; Anxiety & Depression: K-10; Resource utilisation: RUD-Lite |
| 4 | Kunik et al. (2020), USA. RCT | Aggression Prevention Training (APT). 6 × 45 min weekly home visit skill training & telephone wrap-up sessions. Components: Dementia education, recognising and management of pain, communication skills, increasing pleasant activities, treatment information, relaxation techniques and a self-help guide | 114 dyads. 3, 6, and 12 months | Incidence of aggression: CMAI; Overall pain: PGPI; Depression: GDS; Engagement in pleasant activity: PES-AD | Impact of caregiving: ZARIT-BI; Dyadic relationship: Mutuality scale; Changed behaviour: RMBPC; Anxiety: AISF |
| 5 | Laakkonen et al. (2016), Finland. RCT | Self-management group rehabilitation. 8 × 4 h weekly sessions. Shared expertise and information between participants and facilitators on dementia, medication, nutrition, active lifestyle, marital relationship, caregiving, available social and health services, and advance care planning | 67 dyads. 3 and 9 months | Health-related QoL: 15D; cognitive function: CDRS; and MMSE; the Clock Drawing Test (CDT), Verbal Fluency (VF), Nutritional status: Mini-Nutritional Assessment (MNA) | Health-related QoL: RAND Health Survey 1.0; Managing people with dementia: SCQ; Self-efficacy: Pearlin Mastery Scale (PMS) |

TABLE 1 (Continued)

| No | Author, year, country and study design | Program description | Sample size and follow-up period | Outcomes measured and instruments used for people with dementia | Outcomes measured and instruments used for caregivers |
|----|--|--|----------------------------------|--|---|
| 6 | Nordheim et al. (2019), Germany, RCT | Home-based socio and psychotherapeutic support program. Seven in-home sessions with two individual telephone sessions over 10–12 weeks. Components: Information about dementia, communication training, coping and problem-solving strategies, network and activity analysis, counselling for living space adaptations, and relaxation techniques | 55 dyads. 1 and 6 months | Quality of life: QoL-AD; Activities of daily living: IADL and OPS. Psychosocial resources such as dyadic coping: DCI; social support: F-SOZU; Dyadic relationship: VAS; Depressive symptoms: GDS | Quality of life: WHO QoL-BREF. Competency: SCQ; Psychosocial resources such as dyadic coping: DCI; social support: F-SOZU; Dyadic relationship: VAS; Depressive symptoms: GDS |
| 7 | Prick et al. (2015), Netherlands, RCT (outcomes for caregivers) Prick et al. (2016) (outcomes for people with dementia) | Multicomponent Dyadic Interventions. 8 × 1 h home-based weekly session in the first month then bi-weekly for 6 weeks (3 months total). Components: 30 min of physical exercise, and support (psychoeducation, communication training and planning of pleasant activities) | 57 dyads. 3 and 6 months | Depressive symptoms: GDS, the CDS and DRS-RAI-HC. Physical health: SF-36 and SIP; Behavioural symptom: RMBPC | Depressive symptoms: Dutch CES-D. Impact of caregiving: the Dutch SPICC; Caregiver self-rated changed behaviour for people with dementia: RMBPC; Self-rated general health: the standard single-item scale; Salivary cortisol level |
| 8 | Teri et al. (2020), USA. Pre-test/post-test | Reducing Disability in Alzheimer's Disease-NorthWest (RDAD-NW) conducted in-home over 6 weeks. Components: Aerobic/endurance, strength, and balance/flexibility exercises, dementia education, training to increase pleasant events, and activator-behaviour-consequence problem-solving approach | 207 dyads. 3, 7 and 13 months | Level of physical activity: Exercise or other aerobic activity for 30 min a day; Functional status: Restricted activity days | Level of physical activity: Exercise or other aerobic activity for 30 min a day; Physical functioning: SF-36; Quality of life: QoL-AD; Depression: CES-D |
| 9 | Villars et al. (2021), France. Pre-test/post-test. | Therapeutic Education in Alzheimer's (THERAD) 2 individual sessions at baseline and at two months, and 4 × 3 h long weekly group session. Components: Tailored program on identifying goals and skills, and knowledge about community resources along with an educational diagnosis tool which was a semi-directive interview with patient-centred communication techniques and educational techniques | 98 dyads. 2 and 6 months | People with dementia and caregiver-reported QoL: QoL-AD; Activities of daily living: IADL | Impact of caregiving: ZBI |

(Continues)

TABLE 1 (Continued)

| No | Author, year, country and study design | Program description | Sample size and follow-up period | Outcomes measured and instruments used for people with dementia | Outcomes measured and instruments used for caregivers |
|---|---|---|---|---|---|
| 10 | Whitlatch et al. (2019), USA. RCT | Support, Health, Activities, Resources and education Program. 6 x 1-2-h weekly sessions. Components: information sessions about diagnosis and communication strategies, care plan, sources of help, identifying goals and strategies | 84 dyads. Weekly and 6-week post-program | Dyadic relationship functioning: Dyadic Relationship Scale, Care-related Agreement Scale, Emotional-Intimacy Disruptive Behavior Scale; Well-being: Dementia Quality of Life Instrument; Satisfaction: self-rated questionnaire developed the study team | Dyadic relationship functioning: Dyadic Relationship Scale, Care-related Agreement Scale, Emotional-Intimacy Disruptive Behaviour Scale; Well-being: Dementia Quality of Life Instrument; Satisfaction: self-rated questionnaire developed the study team |
| 11 | Williams et al. (2018), USA. Pre-test/post-test | Caring About Relationships and Emotions. 10 x 1 h weekly home-based sessions. Components: Couples received a manual at the start of the intervention. Information, instruction, and practice on variety of dementia related communication with a video-recorded conversation | 15 dyads. Weekly and 6-week post-program | Sociable communication: Verbal and Nonverbal Interaction Scale for Care Receivers (VNVIS-CR). Perception of the program: Interviews | Facilitative communication: Verbal and Nonverbal Interaction Scale for Caregiver (VNV I Perception of the program: Interviews, S-CG) |
| 12 | Yu et al. (2019), Hong Kong. RCT | Dyadic Strength-based Empowerment Program for Mild Cognitive Impairment (D-STEP-MCI): 14-week program in three phases. Components: 1st-2nd week, 90-min home-based dyadic sessions identifying strengths in coping with dementia; in 3rd-8th week, 6 weekly empowerment sessions with information, skills and activities; in 9th-14th week, 3 bi-weekly telephone follow-ups monitoring the level of goal attainment | 52 dyads. 14 weeks and 3-month post-program | Cognitive functions: MMSE; Memory: MIC; Neuropsychiatric symptoms: RMBPC; Depression: C-ESD-10 | Caregiver stress: RMBPC; Depression: C-ESD-10 |
| <i>Long-term support programs over 3 months</i> | | | | | |
| 13 | Charlesworth et al. (2016), UK. RCT | <i>Intervention 1:</i> Carer support Program (CSP), 12 x 1 h weekly sessions, then 11 x 2 h fortnightly sessions. Components: listening, encouraging and communication skills. <i>Intervention 2:</i> Group Reminiscence Therapy (RYCT), 12 x 2 h weekly sessions, then 7 monthly sessions. Components: information, discussion, and activities, developing and practicing communication skills. <i>Intervention 3:</i> CSP plus RYCT | CSP: 48 dyads, RYCT: 97 dyads, and CSP-RYCT: 97 dyads. 5 and 12 months | Quality of life: QoL-AD; Health-related quality of life: EQ-5D, HADS, ADCS-ADL, DEMQol; Quality of relationship: QCPR | Mental health-related quality of life: UK SF-12 Health-related quality of life: EQ-5D, HADS, ELS, NPI-D, PANAS, and Quality of relationship: QCPR |

TABLE 1 (Continued)

| No | Author, year, country and study design | Program description | Sample size and follow-up period | Outcomes measured and instruments used for people with dementia | Outcomes measured and instruments used for caregivers |
|----|---|--|--|---|---|
| 14 | Clare et al. (2019), UK. RCT | Cognitive Rehabilitation Therapy. 10 weekly sessions over 3 months, then 4 maintenance sessions over 6 months. Components: identified personal goals and implement strategies for improved function and social participation | 209 dyads. 3 and 9 months | Goal attainment: BGS; self-efficacy: GSES; depression and anxiety: HADS; cognition: RBMT; QoL: DEMQOL | Goal attainment: BGS; Caregiver stress: RSS; Health status: EQ-5D; QoL: WHO QoL-BREF |
| 15 | Cornelis et al. (2018); Belgium. Pre-test/post-test | Multicomponent Rehabilitation Memory Clinic. 25 × 1 h sessions in 12 months. Component: Counselling sessions including assessment and goal setting, rehabilitation interventions (compensatory and environmental strategies, cognitive and behavioural strategies, psychoeducation and home visit) and evaluation of goal attainment | 30 dyads. 12 months | Everyday functioning: BADL-Katz Index; Cognitive functions: MMSE; Mood: GDS-15; Emotional and behavioural disturbances: NPI-Q; QoL: QoL-AD | Emotional disturbances: NPI-Q; Impact of caregiving: ZARIT-BI |
| 16 | Droës et al. (2019), Netherlands. RCT | Individualized Meeting Centres Support Program (iMCSP), 6 months Component: Tailored volunteering activities for people with dementia, coaching for caregivers, online group education | 65 dyads. 6 months | Self-esteem: RSES; Neuropsychiatric symptom: NPI; Experienced autonomy: EAS; Quality of life: DEMQoL & QoL-AD | Impact of caregiving: NPI-burden subscale; Competency: SCQ; Quality of life; Happiness: TOPICS-MDS |
| 17 | Forbes et al. (2018), Canada. Multiple case study | Integrated knowledge translation strategies (iKT). 12 months program. Component: A homecare information package about dementia and local resource, communication skills with people with dementia; online education skills training program for caregivers, and home visit | 17 interviews. 12 month (post-program) | Qualitative interviews: Lived experience, knowledge of services, influence/usefulness of the program | Qualitative interviews: Lived experience, knowledge of services, influence/usefulness of the program |
| 18 | Jeon et al. (2020), Australia. RCT | Interdisciplinary Home-based Reablement Program (I-HARP). 12 × 1.5 h sessions over 4 months. Components: Dementia-specific strategies and cognitive rehabilitation techniques tailored to dyad's need, plus <AU\$1000 for assistive devices/home modification | 9 dyads. 4 and 12 months | Daily activities/independence: DAD; Mobility: LLFDI-CAT; Depression: GDS; Health-related quality of life: EQ5D-3 L | Health-related quality of life: EQ5D-3 L; Impact of caregiving: ZBI |
| 19 | Koivisto et al. (2016), Finland. RCT | Kuopio ALSOVA. 16 days over 24 months. Components: individual education, counselling and support with life situations, AD, available resources, communication, and future plan, as well as group activities | 84 dyads. 12, 24 and 36 months | Delayed institutionalisation: institutionalisation rates; Memory: CDR-SOB; Cognitive function: CERAD-NB and MMES; Daily activities: ADCS-ADL; Behavioural symptoms: NPI; Quality of life: QoL-AD, VAS | Depression: BDI; Orientation of life: SOC; Psychological distress: GHQ; Health-related quality of life: QoL-15D and VAS |

(Continues)

TABLE 1 (Continued)

| No | Author, year, country and study design | Program description | Sample size and follow-up period | Outcomes measured and instruments used for people with dementia | Outcomes measured and instruments used for caregivers |
|----|--|--|-----------------------------------|--|---|
| 20 | Logsdon et al. (2016), USA. Quasi experimental | Memory Care and Wellness Services (MCWS). 2 days x 5 h per week over 6 months. Components: Specialised activities and exercise, care planning, caregiver support, information and referral services | 162 dyads. 3 and 6 months | Cognitive function: MMSE; Quality of life: QoL-AD; Daily activities: IADL; Mood and behavioural disturbance: RMBPC | Quality of life: QoL-AD; Depression: CES-D; Distress: RMBPC; Impact of caregiving: SCB; Stress: PSS |
| 21 | Novelli et al. (2018), Brazil. RCT | The Tailored Activity Program-Brazilian Version. 8 home-based sessions over 4 months. Components: Tailored activities for people with dementia, information and training for caregivers on dementia, daily activities, behaviours and communications | 15 dyads. >4 months | Behavioural/psychological symptoms: NPI; Quality of Life: QoL-AD | Distress: NPI; Impact of caregiving: ZARIT-BI. Quality of Life: QoL scale |
| 22 | Phung et al. (2013), Denmark. RCT | Danish Alzheimer Intervention Study (DAISY) Multi-aspect semi tailored sessions over 8–12 months and follow-up support at 3, 6 and 12 months. Components: Home-based 7 individual and dyad counselling, telephone counselling 5–8 times with 3–4-week intervals, journal keeping on daily life, 5 group courses and an information booklet | 163 dyads. 3, 6, 12 and 36 months | Global cognitive function: MMSE; Depressive symptoms: CDS; Proxy-rated quality of life: EQ-5D and QoL-AD; Behavioural symptoms: NPI; Daily activities: ADCS-ADLs; Mortality and nursing home placement: Danish Civil Registration System | Depressive symptoms: GDS; Quality of life: EQ-VAS |
| 23 | Stanley et al. (2013), USA. RCT | The Peaceful mind program. 12 X weekly in-home Cognitive Behaviour Therapy sessions for 3 months, and then up to 8 telephone calls to 6 months. Components: Monitoring/management of anxiety, deep breathing and other skill learning including coaching people with dementia | 16 dyads. 3 and 6 months | Anxiety: NPI & RAID; Patient's rating worry and anxiety: PSWQ-A & GAI; Depressive symptoms: GDS; Quality of life: QoL-AD | Caregiver's distress: NPI; Depression: PHQ-9 |
| 24 | Woods et al. (2016), UK. RCT | Joint reminiscence intervention (REMCARE). 12 x 2 h weekly sessions followed by monthly maintenance sessions for 7 months with a total of 10 months program. Component: Active and passive reminiscence sessions on different topics, group activities, and a published treatment manual. Maintenance sessions followed a similar pattern | 205 dyads. 3 and 10 months | Quality of life: QoL-AD; Autobiographical memory: AMI; Quality of relationship: QCPR; Depression & anxiety: CSDD, RAID, HADS; Caregiver rated quality of life: QoL-AD-Proxy; General quality of life: EQ-5D-3L & VAS; Functional ability: BADLS; Use of services: CSRI | Caregiver's mental health: GHQ-28; Quality of relationship: QCPR; Depression & anxiety: HADS; Stress specific to care giving: RSS; General quality of life: EQ-5D-3L & VAS; Use of services: CSRI |

Abbreviations: AISF, Anxiety Index-Short Form; AMI, Autobiographical Memory Interview; ADAS-Cog, Alzheimer's Disease Assessment Scale-Cognition; ADCS-ADL, Activities of Daily Living Inventory; BADL-Katz Index, Basic Activities of Daily Living of Katz Index; BADLS, Bristol Activities of Daily Living Scale; BDI, Beck Depression Inventory; BGSJ, Bangor Goal-Setting Interview; CDRS, Clinical Dementia Rating Scale; CDS, Cornell Depression Score; CERAD-NB, Consortium to Establish a Registry for Alzheimer's Disease Neuropsychological Battery; CES-D, Centre for Epidemiological Studies Depression Scale; CMAI, Cohen Mansfield Agitation Inventory; CSDD, Cornell Scale for Depression in Dementia; CSRI, Client Services Receipt Inventory; DAD, Disability Assessment for Dementia; DEMQOL, Dementia Quality of Life; DRS-RAI-HC, Depression Rating Scale of the Resident Assessment Instrument Home Care; EQ-5D, European Quality of Life on Five Dimension; EAS, Experienced

TABLE 1 (Continued)

autonomy scale; GDS, Global Deterioration Scale; GHQ-28, General Health Questionnaire; GPIS, Geriatric Pain Intensity Scale; GSES, Generalized Self-Efficacy Scale; SPICC, Dutch Self-Perceived Pressure from Family Care; HADS, Hospital Anxiety and Depression Scale; IADL, Instrumental Activities of Daily Living; K-10, Kessler Psychological Distress Scale; LLFDI-CAT, Late Life Function and Disability Instrument Computer Adaptive Test; MIC, Memory Inventory for Chinese; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory; NPI-D, Caregiver Distress Scale of the Neuropsychiatric Inventory; NPI-Q, Neuropsychiatric Inventory Questionnaire; OPS, Older Adults Over protection Scale; PANAS, Positive scale from the Positive and Negative Affect Schedule; PEAS-AD, Pleasant Events Activity Schedule-Alzheimer Disease; PSMS, Physical Self-Maintenance Scales; PSS, Perceived Stress Scale; QCPR, Quality of Carer-Patient Relationship Scale; QoL-15D, Quality of Life scale 15 Dementia; QoL-AD, Quality of life in Alzheimer Disease; RAID, Rating Anxiety in Dementia; RBMT, Rivermead Behavioural Memory Test; RCT, Randomised Control Trial; RMBPC, Revised Memory and Behavior Problem Checklist; RSES, Rosenberg Self-esteem Scale; RSS, Relatives' Stress Scale; SCB, Screen for Caregiver Burden; SF-12, Short Form Health Survey; SIP, Sickness Impact Profile; SOC, Sense of Coherence Scale; SCQ, Sense of Competence Questionnaire; TOPICS-MDS, The Older Persons and Informal Caregivers Survey Minimum DataSet; UK SF-12, UK Short Form-12 Health Survey; VAS, Visual Analog Scale; WHO QoL-BREF, Short version of the WHO Quality of Life questionnaire; ZARIT-BI, Zarit Burden Interview.

showed significant improvement at three months, but not at the six-month follow-up. Another eight studies found no significant effects on quality of life outcomes. While the program components overlapped across studies, it was unclear why two programs reported significant improvement in quality of life for the people with dementia and others not.

Cognitive function outcomes for people with dementia

Three of the 12 studies measuring cognitive function reported the intervention group had significantly less cognitive decline, or memory improvement compared with the control group. Of them, two (Nordheim et al., 2019; Yu et al., 2019) provided home-based sessions on information, identifying strengths and tailored activities with follow-up individual telephone counselling to monitor goal attainment within 10–14 weeks. Despite providing customised activities, the improvement in cognitive function was not sustained three months after the program (Yu et al., 2019). As the author stated, it could be because the intervention focused on enhancing roles and social engagement of the participants in daily life to influence cognitive outcomes and no active and structured cognitive training component was incorporated. Another study (Laakkonen et al., 2016) provided 32 h (8 × 4 h weekly sessions) of therapeutic rehabilitation program consisting of active lifestyle support, nutrition and care planning. Two studies reported heterogeneous results indicating that participants' perceived autonomy and self-esteem showed a small to moderate benefit after six months, but the benefit was not significantly different to the control groups (Dröes et al., 2019); similarly while behavioural symptoms improved, severity of dementia increased at six and 12 months follow-up period (Gresham et al., 2018). Another seven studies had no significant differences or cognitive function declined significantly in the intervention group.

Psychological and mental health outcomes for people with dementia

Only one of the 12 studies which measured various aspects of mental health for the participants reported significant improvements in depression at 14 weeks post-intervention and three months after the intervention than in the control group (Yu et al., 2019). Along with information sessions, the intervention included 90 min of home-based dyadic sessions identifying strengths in coping with dementia, and three bi-weekly telephone follow-up calls monitoring goal attainment. Four studies showed improvement for some aspects of mental health, but not for others. Another six studies did not show any improvement in the intervention groups. In a qualitative interview, people with dementia were concerned about stigma around dementia and their safety (Forbes et al., 2018). It was unclear if the intervention had any impact on their concern.

Physical health outcomes for people with dementia

One of the nine studies on physical health resulted in a significant reduction in respiratory rate at post-program (Collins et al., 2018). This study provided six, two-hour weekly sessions on psychoeducation, mindfulness practice, breathing techniques and compassion.

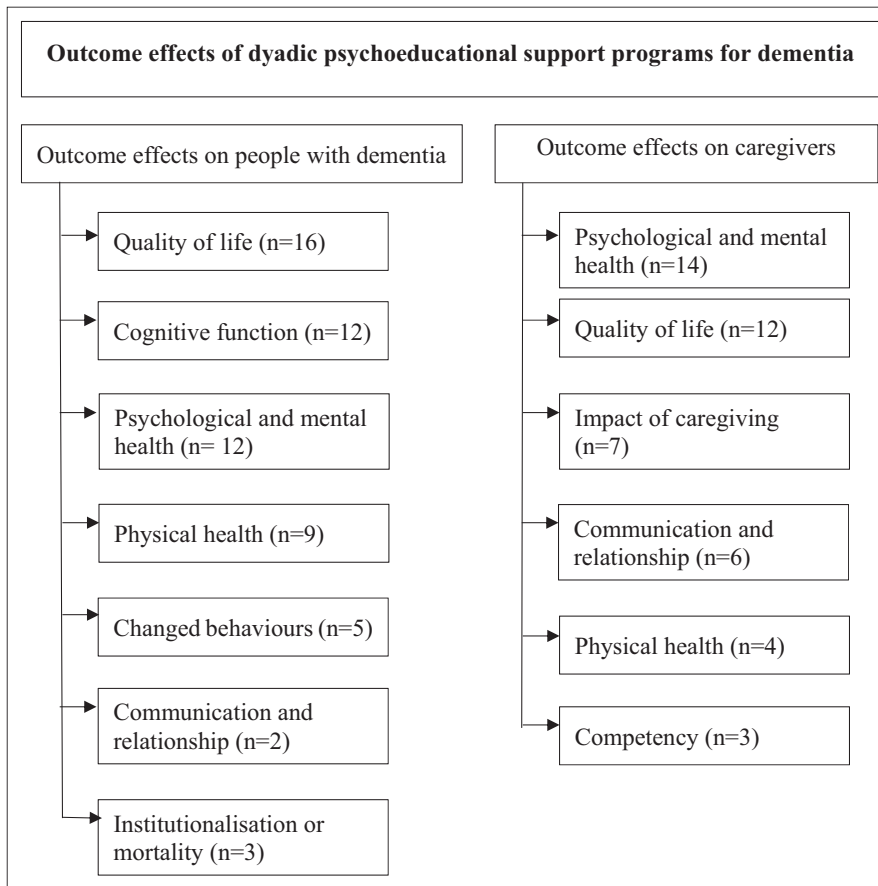


FIGURE 2 Categories and sub-categories of outcome effects of dyadic psychoeducational support programs for dementia.

Another two studies (Jeon et al., 2020; Teri et al., 2020) reported marginal improvement in functional independence or heterogeneous results. The interventions were offered for six weeks (Teri et al., 2020), and over four months (Jeon et al., 2020) and consisted of multicomponent activities including exercise, behaviour techniques, rehabilitation techniques and other supports according to dyads' needs. Six studies showed either no significant results, or significant decline in daily functioning.

Behavioural outcomes for people with dementia

Two of the five studies assessing various aspects of behavioural changes described a significant reduction in severity of emotional and behavioural symptoms (Novelli et al., 2018; Yu et al., 2019). Both studies provided tailored home-based activities to improve outcomes over three to four months. In one study (Cornelis et al., 2018), behavioural symptoms remained stable when compared with control groups. This study provided home-based activities and education. Another two (Kunik et al., 2020; Logsdon et al., 2016) found no significant differences between the program and control groups. The programs in both studies had tailored specialised activities and care planning, and one had home-visit skill training and telephone wrap-up sessions.

Communication and relationship outcomes for people with dementia

One of the two studies describing the program effect on communication and relationship reported significant improvement in goal

attainment at three and six months after completion of the program (Clare et al., 2019). This study provided cognitive rehabilitation therapy along with identifying personal goals and implemented strategies to achieve those goals. The other one found no significant effect (Nordheim et al., 2019). This study included seven home-based socio and psychotherapeutic support program with two individual telephone sessions over 10–12 weeks, and provided information about dementia, communication training, coping and problem-solving strategies, network and activity analysis, counselling for living space adaptations and relaxation techniques.

Institutionalisation and mortality outcomes for people with dementia

None of the three studies examining admission into residential-care facilities or mortality found any positive effect of the program. Of them, one study (Gresham et al., 2018), in the absence of follow-up data, predicted that the program group were more likely to be in residential care at 12 months.

3.4.2 | Outcomes effects on family caregivers

The outcome effects (Table 3) on family caregivers were grouped into six categories: psychological and mental health ($n = 14$), quality of life ($n = 12$), impact of caregiving ($n = 7$), communication and relationship ($n = 6$), physical health ($n = 4$) and competency ($n = 3$).

TABLE 2 Effects of dyadic psychoeducational support programs on people with dementia by outcome category

| Outcome category and outcome measured | Studies reporting significant effects | Studies reporting moderate or heterogeneous effects | Studies reporting no sig. effects or worsened |
|---|--|--|---|
| Quality of life: health-related quality of life | <p>Collins et al. (2018): Significant increase in quality of life at post-assessment ($t(8) = -3.16, p = .01$), with a large effect size (dRM) of 1.03 in 6 weeks.</p> <p>Cornelis et al. (2018). QoL improved ($Z = -2.7, p = .006$), CI = 0.003 to 0.005 in 12 months</p> | <p>Charlesworth et al. (2016). No significant effect at 12 months, but the interaction between the two interventions they examined was significant ($p = .02$), suggesting the combination of the two interventions might be beneficial.</p> <p>Dröes et al. (2019). Intervention group showed a positive effect ($B = 0.17, CI = 0.03$ to $0.30, p = .021$) after 6 months, but did not differ significantly between control groups.</p> <p>Jeon et al. (2020). Intervention group had a 5-point improvement at 4 and 12 months, while the control group showed a decrease of 3.38 points in HRQoL with difference of 8.38 and effect size of 0.46.</p> <p>Novelli et al. (2018). Caregiver rating showed significant improvement in QoL ($p = .01$, Cohen $d = 0.56$), but participants ratings did not show differences after 4 months.</p> <p>Stanley et al. (2013). Significant improvement at 3 months, but not at 6 months.</p> <p>Villars et al. (2021). While there was a significant difference in self-reported patients' QOL at 2 months ($p = .0483$) or 6 months ($p = .0154$), no significant difference in caregiver-reported patients' QOL</p> | <p>Clare et al. (2019)</p> <p>Cove et al. (2014)</p> <p>Koivisto et al. (2016)</p> <p>Laakkonen et al. (2016)</p> <p>Logsdon et al. (2016)</p> <p>Nordheim et al. (2019)</p> <p>Phung et al. (2013)</p> <p>Woods et al. (2016)</p> |
| Cognitive function: neuropsychiatric symptoms, memory, verbal fluency | <p>Laakkonen et al. (2016): Cognitive scores (VF, CDT) improved at 9 months ($-0.38, CI = -1.03$ to 0.27) in intervention group and $-1.60, CI = -2.26$ to -0.94 for controls ($p = .011$).</p> <p>Nordheim et al. (2019): Decline in cognitive functioning was less steep in intervention group at 6 months follow-up (interaction term $B = 0.8, p < .05$).</p> <p>Yu et al. (2019). Improvement in CF at post-test period ($\beta = -1.79, SE = 0.69, p < .001$). Memory improved and was maintained after 3 months ($\beta = 8.16, SE = 3.13, p = .009$)</p> | <p>Dröes et al. (2019). Effect size on perceived autonomy and self-esteem showed a small to moderate benefit after 6 months but did not differ significantly between control groups.</p> <p>Gresham et al. (2018). While behavioural symptoms improved on NPI ($F[2156] = 16.9, p < .001$), dementia severity increased on GDS ($F[1.7, 135.1] = 43.5, p < .001$) significantly at 6 and 12 months</p> | <p>Charlesworth et al. (2016)</p> <p>Clare et al. (2019).</p> <p>Cornelis et al. (2018). Cognitive function significantly declined ($Z = -1.9, p = .046, CI 0.043-0.051$) after 12 months.</p> <p>Cove et al. (2014).</p> <p>Koivisto et al. (2016): Intervention group performed significantly worse in cognitive function and memory.</p> <p>Logsdon et al. (2016).</p> <p>Whitlatch et al. (2019)</p> |

(Continues)

TABLE 2 (Continued)

| Outcome category and outcome measured | Studies reporting significant effects | Studies reporting moderate or heterogeneous effects | Studies reporting no significant effects or worsened |
|---|---|--|---|
| Psychological and mental health: depression, anxiety, emotional well-being, mood, self-esteem and engagement in pleasant event | Yu et al. (2019). Depression improved (post-test: $\beta = 2.67$, $SE = 1.12$, $p = .017$; and after 3 months: $\beta = 3.57$, $SE = 1.31$, $p = .006$) | Collins et al. (2018): Only 57% participants with borderline or abnormal baseline scores showed significant improvement at post-assessment. Significant reduction in depression ($t [19] = 2.40$, $p = .03$), but reduction in anxiety was not significant in 6 weeks. Jeon et al. (2020): Depression scored slightly improved with difference between control and intervention in 4 months ($CI = -0.64$, -2.11 , 0.84) and in 12 months ($CI = -1.18$, -2.98 , 0.63). Logsdon et al. (2016). No significant differences between two groups at 3 months. However, after 6 months, participants exhibited significantly fewer depressive behaviours ($t = -.13$ [$.60$] $p = .02$) than comparison group. Stanley et al. (2013). Significant improvement on patient's anxiety at 3 months but not at 6 months. Group differences in anxiety and depressive symptoms were not sig at 3 or 6 months. | Clare et al. (2019). Cornelis et al. (2018). Significant decline in ($Z = -2.5$, $p = .001$), $CI = 0.016$ to 0.021 after 12 months. Forbes et al. (2018). Prick et al. (2016). Phung et al. (2013). No improvement in depression. Whitlatch et al. (2019). Woods et al. (2016). Depression anxiety |
| Physical Health: physical functioning, independence, pain, mobility, restricted activities, respiratory rate, daily activities and autonomy | Collins et al. (2018): Compared with baseline, a significant reduction in respiratory rate at post-intervention ($t (12) = 4.34$, $p < .001$), with a large effect size (dRM) of 1.20 in 6 weeks | Jeon et al. (2020): Intervention groups had a marginal improvement ($DAD = 0.78$ point) in functional independence while control group declined by 4.78 points with difference of 5.56 and effect size of 0.52 . Teri et al. (2020) levels of PA increased sig. SF-36 physical functioning and physical role function was not improved with treatment | Cornelis et al. (2018). Daily functioning declined significantly ($Z = -3.2$, $p = .001$, $CI = 0.000$ to 0.001). Koivisto et al. (2016): Daily activities scores were low. Logsdon et al. (2016) Nordheim et al. (2019). Prick et al. (2015) Villars et al. (2021) |
| Changed behaviour: aggression, agitation, emotional/behavioural state, irritability and delusions | Yu et al. (2019). Reduction in symptom severity (post-test: $\beta = 2.90$, $SE = .84$, $p = .001$; at 3 months: $\beta = 3.01$, $SE = 1.11$). Novelli et al. (2018). Significant reduction in number, frequency and intensity of emotional/behavioural state and total NPI score ($p = .00$; Cohen $d = 0.95$) after 4 months | Cornelis et al. (2018). Emotional and behavioural state remained stable at the end of the programme compared with control group ($Z = -0.5$, $p = .585$, $CI = 0.588-0.607$) in 12 months | Kunik et al. (2020) Logsdon et al. (2016) |

TABLE 2 (Continued)

| Outcome category and outcome measured | Studies reporting significant effects | Studies reporting moderate or heterogeneous effects | Studies reporting no significant effects or worsened |
|---|--|---|---|
| Communication and relationship: goal setting, goals attainment and coping | Clare et al. (2019). Goal attainment improved at 3 months and retained at 6 months later [mean change in the intervention: 2.57; mean change in control: 0.86; Cohen's $d = 0.97$, 95% CI 0.75 to 1.19], corroborated by caregiver ratings (Cohen's $d = 1.11$, 95% CI 0.89 to 1.34) | | Nordheim et al. (2019) |
| Institutionalisation and mortality | | | Gresham et al. (2018), Authors did not have follow-up data, so did sensitivity analysis and reported, intervention were more likely to be in a residential care home at 12 months (OR 5.8, CI 2.8–11.6, $p < .001$). Phung et al. (2013). at 36 months. Koivisto et al. (2016) |

Abbreviations: CI, confidence interval; GDS, global deterioration scale; HRQoL, health-related quality of life; NPI, neuropsychiatric inventory; OR, odds ratio; QoL, quality of life; SE, standard error of mean.

Psychological and mental health outcomes for caregivers

Two of the 14 studies which measured various aspects of psychological and mental health for the caregivers reported significant reduction in distress and emotional disruption (Novelli et al., 2018; Whitlatch et al., 2019). Both provided individual-focused educational and training activities, and one offered 12 sessions within six weeks (Whitlatch et al., 2019) while the other conducted eight sessions over a four-month period (Novelli et al., 2018). Four studies (Collins et al., 2018; Logsdon et al., 2016; Stanley et al., 2013; Yu et al., 2019) reported heterogeneous effects; some caregivers with borderline symptoms showed improvement (Collins et al., 2018); caregivers showed less distress compared to a comparison group at a six-month assessment but not at three months (Logsdon et al., 2016), anxiety and stress improved post-intervention at three months, but was not sustained at six-month follow-up (Stanley et al., 2013; Yu et al., 2019). Outcome improvements may be visible in short-term assessment, but inconsistent across studies. Another eight studies found no changes, or no significant improvement or conditions worsened.

Quality of life outcomes for caregivers

None of the 12 studies which measured caregivers' quality of life found any significant improvements; two showed heterogeneous effects (Laakkonen et al., 2016; Novelli et al., 2018) and another 10 studies did not report any significant differences within the groups, despite some studies providing individual education and activities.

Impact of caregiving

One of the seven studies reported significant decreases in the impact of caregiving score after six months of the program (Dröes et al., 2019). The intervention included individualised activities for people with dementia, individualised coaching for caregivers and online learning for both in 25 sessions over 12 months. Another six studies did not notice any effects on impact of caregiving.

Communication and relationship outcomes for caregivers

Of the six studies measuring the impact on communication and relationship, two found significant improvement (Charlesworth et al., 2016), and needs met (Gresham et al., 2018). Both provided individualised focus support and activities with one providing 14 sessions during a five-day study period and the other over a seven-month period. Another four studies did not observe any changes between groups or had a negative effect.

Physical health outcomes for caregivers

A significant reduction in respiratory rate post-program when compared with baseline data was observed in one study (Collins et al., 2018), while three studies did not report any significant effect in caregivers' physical health.

Competency and knowledge outcomes for caregivers

Forbes et al. (2018) examined the effect of the intervention through qualitative interviews and reported that caregivers

TABLE 3 Effects of dyadic psychoeducational support programs on caregivers by outcome category

| Outcomes measured | Studies showing significant improvement | Studies showing moderate or heterogeneous effects | Studies showing no significant improvement |
|---|--|---|--|
| Psychological and mental health: depression, anxiety, emotional well-being, support programs and psychological distress | Novelli et al. (2018). Significant reduction in distress ($p = .00$; Cohen $d = 0.87$) after 4 months. Whitlatch et al. (2019). Improved emotional disruption ($F = 4.81$, $p = .030$) in 6 weeks | Collins et al. (2018). 50%–80% caregivers with borderline or abnormal baseline scores showed significant improvement in 6 weeks. Reduction in depression and anxiety, but not significant. Logsdon et al. (2016). No significant differences between groups at 3 months. However, caregivers exhibited significantly less distress and depressive problems ($t = -0.23$ [0.86], $p = .01$) than comparison group after 6 months. Stanley et al. (2013). Anxiety & distress significantly decreased at 3 months, but not at 6 months. No changes in depression. Yu et al. (2019). Stress improved at post-test ($\beta = 3.29$, $SE = 1.50$, $p = .028$) but not sustained after 3 months endpoint. Depression improved and sustained after 3 months ($\beta = 372$, $SE = 1.51$, $p = .014$) | Clare et al. (2019) Cornelis et al. (2018) Gresham et al. (2018) Jeon et al. (2020) Koivisto et al. (2016) Phung et al. (2013) Prick et al. (2015) Woods et al. (2016) Anxiety level increased at 10 months end point (mean difference 1.25 [0.25 to 2.26], $F = 8.28$, $p = .04$) |
| Quality of life: health-related quality of life | | Laakkonen et al. (2016). Only physical component improved at 3 months (RAND-36, mean change 1.0, CI -0.5 to 2.4 for intervention, and -2.0, CI = -3.5 to -0.4, $p = .006$ for control). Novelli et al. (2018). Caregiver rating showed significant improvement in QoL ($p = .02$, Cohen $d = 0.57$), but ratings by people with dementia did not show differences after 4 months | Clare et al. (2019) Charlesworth et al. (2016) Cornelis et al. (2018) Dröes et al. (2019) Gresham et al. (2018) Jeon et al. (2020) Koivisto et al. (2016) Nordheim et al. (2019). A negative association reported, but not significant. Phung et al. (2013) Woods et al. (2016) |
| Impact of caregiving | Dröes et al., 2019. Support impact decreased of (-)3.38 after 6 months in intervention group, whereas control group had an increase in impact of caregiving with 1.24 score (difference 4.62) | | Gresham et al. (2018) Laakkonen et al. (2016) Jeon et al. (2020) Logsdon et al. (2016) Prick et al. (2015) Villars et al. (2021) |

TABLE 3 (Continued)

| Outcomes measured | Studies showing significant improvement | Studies showing moderate or heterogeneous effects | Studies showing no significant improvement |
|---|--|---|--|
| Communication and relationship: coping, needs met | Charlesworth et al., 2016. Improved quality of relationship (mean diff. 1.11, CI = 0.00 to 2.21, $p = .05$) and perceived quality of caring relationship (mean difference 3.13, 95% CI 0.42 to 5.83, $p = .03$) at 5 and 12 months. Gresham et al., 2018. Caregivers reported needs being met increased at 6 and 12 months ($F_{1,7, 123.6} = 26.9$, $p < .001$) | | Cove et al. (2014): no changes over time or between-group at follow-up. Kunik et al. (2020): no changes over time. Nordheim et al. (2019): Negative dyadic coping was associated with couple with poor dyadic relationship. Woods et al. (2016) |
| Physical health: respiratory rate and general health | Collins et al. (2018). Significant reduction in respiratory rate at 6 weeks ($t_{14} = 2.72$, $p = .02$), with a medium effect size dRM 0.70 | | Clare et al. (2019) health status. Prick et al. (2015) general health. Gresham et al. (2018). health status |
| Competency: self-esteem, efficacy, knowledge and skills | Forbes et al. (2018). Learned appropriately responding to people with dementia at 12 months. Improved communication to share experience and knowledge with others | | Dröes et al. (2019) Laakkonen et al. (2016) |

Abbreviations: CI, confidence interval; HRQoL, health-related quality of life; OR, odds ratio; QoL, quality of life; SE, standard error of mean.

learned how to deal with stress, goal setting and knowledge of dementia:

Probably how to deal with the stress and day to day, because the support group, those people that ask questions and they have ideas, try this or try that, and this way or try it that way. So, I think that's helpful.

(Forbes et al., 2018, p. 225)

The 12-month program in their study included home visits and a homecare information package about dementia and local resources,

communication skills with people with dementia, support groups and online education skills training program for caregivers. The authors reported that the strategies the caregivers learned from the intervention assisted them in appropriately responding to the persons living with dementia. The other two studies (Dröes et al., 2019 and Laakkonen et al., 2016) focussing on caregivers' competency and knowledge did not report any significant improvement.

Positive outcomes for the dyads

Only two of the 27 dyadic programs resulted in consistent positive results for the dyads (Collins et al., 2018; Novelli et al., 2018). One

provided two-hourly sessions in six weeks with multicomponent activities including psychoeducation, mindfulness, breathing and compassion (Collins et al., 2018). The other study also provided eight tailored home-based multicomponent activities over four months including information, daily activities and communication (Novelli et al., 2018). These studies likely to be provided goal oriented and tailored activities and outcomes measured were more congruent with the program activities. Another two studies reported moderate or heterogeneous effects on the dyads' outcomes (Logsdon et al., 2016; Stanley et al., 2013). The programs in these studies included individualised multicomponent training and activities and were offered over a six to 12-month period. Five studies reported positive outcomes for people with dementia only (Clare et al., 2019; Cornelis et al., 2018; Laakkonen et al., 2016; Nordheim et al., 2019; Yu et al., 2019), and five studies reported positive results for caregivers only (Charlesworth et al., 2016; Dröes et al., 2019; Forbes et al., 2018; Gresham et al., 2018; Whitlatch et al., 2019). The results indicated that educational interventions were effective and consistent when these were goal oriented, individually focused and combined with additional supportive components.

4 | DISCUSSION

This systematic review of 24 studies evaluating 27 programs provides information on the best evidence of dyadic dementia psychoeducational support programs on the outcomes of people with dementia and their family caregivers. We included only those studies which not only delivered programs for both people with dementia and their caregivers, but also measured outcomes for the dyads. Family caregivers of people with dementia are often called the "invisible second patients" who experience high rates of physical and mental health issue, burden as well as social isolation (Brodaty & Donkin, 2009). The dyadic psychoeducational support programs in this review provided a range of multicomponent activities including dementia psychoeducation, exercise, behavioural training, coping strategies, cognitive therapy, reminiscence therapy, problem solving and/or counselling, in a combination of single and group sessions which are consistent with previous studies (Sörensen et al., 2006; Vandepitte et al., 2016). The programs were delivered between six weeks and two years in a community setting or at participants' homes. The outcome effects on people with dementia reported in the included studies were grouped into seven categories: quality of life, cognitive function, psychological and mental health, physical health, changed behaviour, communication and relationship, institutionalisation or mortality. The outcome effects on family caregivers reported in the included studies were grouped into six categories: psychological and mental health, quality of life, impact of caregiving, communication and relationship, physical health and competency. The evidence from the reviewed studies suggests that the positive effects of short-term and long-term programs are inconsistent and showed that educational programs when combined with other additional psychosocial aspects had positive outcomes for the dyads. This review also found that tailored activities

to address individual needs have consistent benefits on psychological and behavioural symptoms, depressive symptoms, quality of life and impact of caregiving.

Multicomponent interventions were reported to be more effective in improving symptoms for either people with dementia or caregivers or both (Laver et al., 2017; Smits et al., 2007). The effectiveness of goal-specific programs on dyadic outcomes are consistent with the literature. In their systematic review, Van't Leven et al. (2013) reported that interventions which focused on one or more particular aspect of symptoms and actively trained to improve those symptoms for the participants were beneficial. Goal-oriented multicomponent interventions also generated positive outcomes on psychological health and self-efficacy of family caregivers in Vandepitte et al. (2016) review. Another systematic review and meta-analysis of 22 psychosocial interventions reported that multicomponent interventions designed to address specific outcomes had a small to moderate significant effect in reducing the impact of caregiving, depression and general health (Teahan et al., 2020). The authors highlighted that multicomponent intervention targeting impact of caregiving also included dementia education, and thus suggested that education as single component intervention could be effective at reducing impact of caregiving for caregivers. This is in contrast with an earlier systematic review by Selwood et al. (2007) who found that while goal-specific individualised behavioural management therapy was effective in elevating family caregivers' psychological health, dementia education by itself was not an effective intervention for caregivers. In our review, we did not examine the effect of other psychosocial components and educational components separately. As such, it was not possible to establish a clear positive effect of educational interventions itself on the dyad's quality of life, cognitive function, psychological and mental health, physical function, behavioural state, spouse relationship and institutionalisation or mortality.

Due to the deteriorating nature of dementia and progressive cognitive impairment in people with dementia, improvement in cognitive function is challenging. Initial improvements immediately following interventions may not be sustained in the long run. As observed in some of the studies in this review, those which measured cognitive function of people with dementia reported minor positive changes or no changes, and if immediate significant changes were observed, those changes were not maintained despite providing tailored activities on an individual level (Charlesworth et al., 2016; Dröes et al., 2019; Yu et al., 2019). Yet, it is safe to suggest that goal-oriented long-term support programs would be more beneficial than goal-oriented short-term programs for dyads. It is noteworthy that the effectiveness of support programs was based on the severity of the symptoms of people with dementia. As Laver et al. (2017) noted in their systematic review, interventions were more effective in reducing levels of depression and impact of caregiving for caregivers when people with dementia had milder symptoms, whereas interventions were more effective in improving caregivers' quality of life when their care recipients had moderate to severe symptoms of dementia. Due to the heterogenous studies in this review, performing an analysis to

examine severity of dementia symptoms and efficacy of the interventions was beyond the scope of this review. Additionally, most of the studies in this review did not evaluate programs based on severity of symptoms of people with dementia.

Even though psychoeducational support programs are highly recommended and receiving more attention for managing symptoms of dementia, in reality psychoeducational support programs are mostly complementary to pharmacological treatment for people with dementia or respite care for the family caregivers. As noted, pharmacotherapy continues to be the popular treatment option in both dementia care recipients and caregivers (Grace et al., 2016). Further, the prevalence of any psychotropic medication use among family caregivers of people with dementia is about 30.7% to 64.4% (Maust et al., 2020; Thomann et al., 2022). The articles in this review did not investigate the effects of any pharmacological treatments. As such, we do not know if the effects of the programs were solely due to the multicomponent psychoeducational aspects or that of other nonreported pharmacological treatments or a combination of both.

4.1 | Strengths and limitations

We believe the use of mixed methods research approach is the best methodology to investigate such complex interventions in such heterogenous care situations in dementia research. The evidence of the effectiveness of dyadic psychoeducational support programs on people with dementia and family caregivers' outcomes in this study is quite weak, yet the use of mixed methods research studies provides a comprehensive analysis of the phenomenon and a more complete basis for complex decision-making (Stern et al., 2020). The rigour of this review was achieved through systematic and standardised literature searches, quality assessment of the articles using standardised assessment tools by at least two reviewers, thorough data extraction into analyses and reporting of the findings. Some other limitations also need to be acknowledged. Due to lack of resources to undertaking translation, we included studies published in English which might limit the generalisability of the findings in this review. Conference paper and pre-print articles were excluded due not be peer-reviewed up until January 2021. Inclusion of those studies could have resulted in different conclusions being drawn in this review. Synthesising results were hampered by the heterogeneous nature of the studies which varied in quality, intervention types, study design, study duration, data collection methods, sample size, outcome measured and follow-up period. While most of the studies used validated measurement instruments, they sometimes used different combinations of subscales and/or used multiple instruments for similar outcomes which challenged interpretation and comparisons of results. The severity of dementia varied in the reviewed studies and/or was not measured which also made it impossible to generalise conclusions across studies. Further, it was not possible to determine whether the intervention was the significant factor or it was the program facilitators' physical presence and delivering the dyadic session.

5 | CONCLUSION AND RELEVANCE TO CLINICAL PRACTICE

This review found that dyadic multicomponent psychoeducational programs which were targeted and tailored to address individual needs to identify skills and goals, and provided support to attain specific outcomes appeared to be more beneficial than programs which were not goal oriented and tailored to individual needs. The findings may guide clinicians, professionals and policy makers when designing and implementing dementia interventions. Although we did not find strong evidence to suggest that long-term programs had a positive effect on dyadic outcomes, given the progressive deteriorating nature of the condition, and the increase in the number of people with dementia being cared for at home, delivering interventions for a long-term period than short-term can be beneficial to maintain the positive effects on the dyads. Service providers may need to take the long-term interventions into considerations when applying for funding. Further research is required to examine the effectiveness of programs and severity of symptoms. Future research also should focus on identifying the cost-effective means of delivering effective and goal-oriented multicomponent programs for the dyads. Combination of face-to-face and web-based technology can be considered as cost-effective and sustainable support program.

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DATA AVAILABILITY STATEMENT

Data are in Tables 1-3 included in the article.

ETHICS STATEMENT

This systematic review used data from previous published studies in which informed consent was obtained by primary investigators. As such, ethics approval was not required for this review.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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