Dementia module - evidence profile DEM1: Psychosocial interventions for carers of people with dementia

WHO mhGAP guideline update: Mental Health Gap Action Programme (mhGAP) guideline for mental, neurological and substance use disorders

2023

World Health Organization

Contents

Mental Health Gap Action Programme (mhGAP) guideline for mental, neurological and substance use disorders, available at: https://www.who.int/publications/i/item/9789240084278

1.Background

Worldwide, estimated 55 million people have dementia, with about two thirds living in low- and middle-income countries. Caring for a person living with dementia can be both rewarding and challenging. A great deal has been researched on the negative impact of caregiving on the physical, psychological, social, and emotional health and well-being of family or informal carers, often leading to a broader financial and societal impact. Concurrently, several decades of research in the field of dementia care have shown such negative aspects of caregiving can be prevented, managed and/or minimized through various non-pharmacological interventions.

In the last mhGAP (2016), various psychosocial/non-pharmacological interventions were recommended including psychoeducation, cognitive behavioural therapy (CBT), counselling, case management, general support, training of caregivers, multi-component interventions, respite care, and peer-to-peer/self-help groups. Whilst strength of evidence was somewhat low, such interventions were deemed to be critically important in reducing caregiver burden, depressive symptoms, and well-being/quality of life, and improved care of the person with dementia, all of which may play a role in improving well-being of the care recipient.

Following a preliminary review of research studies using MEDLINE (2019-2021) in December 2022, the review team, and the World Health Organization (WHO) methodology team agreed that a systematic review of existing relevant, up to date, high-quality systematic reviews would be deemed to provide sufficient evidence for this update of mhGAP guideline recommendations for carers of people living with dementia. The aim of this review was to identify current evidence on the effectiveness of psychosocial interventions for carers of people with dementia in improving outcomes.

2. Methodology

The process for evidence retrieval and synthesis is based on Chapter 8 of the WHO handbook for guideline development *https://apps.who.int/iris/handle/10665/145714*. A summary of the process is also available in the process note in Appendix I: mhGAP process note.

2.1. PICO question

For carers of people with dementia, are psychosocial interventions effective in improving their outcomes?

Population (P): Carers of people living with dementia.
Intervention (I): Psychosocial intervention, Psychoeducation, cognitive-behavioural therapy, counselling, case management, general support, training of caregivers, multi-component interventions, respite care, peer-to-peer/self-help groups.
Comparator (C): Placebo/comparator.
Outcomes (O):
List critical outcomes:

- Critical outcome 1: burden (subjective/objective).
- Critical outcome 2: depressive symptoms.
- Critical outcome 3: well-being/quality of life.
- Critical outcome 4: improved care of the person with dementia.

List important outcomes:

- Important outcome 1: sleep.
- Important outcome 2: skills/knowledge.
- Important outcome 3: self-efficacy.
- Important outcome 4: chronic stress (e.g. measured by cortisol levels)
- Important outcome 5: physical health.

Subgroups: N/A

2.2. Search strategy[1]

We searched the following databases: MEDLINE, EMBASE, PsycInfo, Cumulative Index to Nursing and Allied Health Literature (CINAHIL), Scopus, African Index Medicus, Index Medicus for the Eastern Mediterranean Region, Index Medicus for the South-East Asian Region, Latin American and Caribbean Health Sciences Literature, and Western Pacific Region Index Medicus, EPISTEMONIKOS (https://www.epistemonikos.org)

Repositories of systematic reviews protocols were also searched e.g. International prospective register of systematic reviews (PROSPERO), Open Science Framework (OSF), and Cochrane to identify additional systematic reviews.

Searches were limited to title, abstract, keywords and subject headings. Wildcards (*) were used to accommodate variations of American/British English.

Terms/Concepts used included, but not limited to, the following: (caregiver OR carer) AND (dementia OR Alzheimer) AND (respite OR "day care" OR "day cent*" OR "adult day service" OR psychoeducation OR "cognitive-behavio* therapy" OR Counsel* OR "case management" OR support OR training OR "peer-support" OR "self help") AND (systematic reviews).

For dementia related search terms where, applicable, we used MeSH (exp) which included all types of dementia. Where MeSH was not applicable, we used dementia and Alzheimer's disease. Where applicable, we combined MeSH and non-MeSH terms for all search terms.

Selection criteria applied to search terms were based on:

- *Type of studies:* Primarily systematic reviews and/with meta-analysis. We excluded meta/umbrella/systematic overview of systematic reviews, narrative reviews, qualitative reviews, realist reviews, scoping reviews, and protocols.
- *Types of participants:* Carers of people with dementia (all types of dementia). Carers were included if they were informal carers (family, relative, friends, or unpaid carers). We excluded paid carers/care workers. (Note: in search terms, sibling, daughter, son, wife, husband, offspring were also included)
- *Types of interventions: all non-pharmacological interventions for carers.* See PICOS (the interventions were not exhaustive lists and other interventions not included in PICOS were considered if they were non-pharmacological interventions for carers of people living with dementia)
- *Types of outcome measures:* all primary and secondary outcomes were considered in the selection of studies. However, they were not used for initial search processes (See PICOS)
- *Published language of study*: No language limit.
- *Date range*: Last three years (January 2019 – January 2022)

See appendix II for search terms and results of each bibliographic database, and repository of systematic reviews.

It was deemed appropriate to include more than one systematic review for the same PICO, as different reviews may match different outcomes of a PICO. However, when more than one systematic review was available for the same PICO outcome, one review was selected, based on quality, relevance, search comprehensiveness and date of last update. The preference was given to reviews of highest quality (High and Moderate based on A Measurement Tool to Assess Systematic Reviews-II [AMSTAR-II] rating) which might need to be supplemented with additional material, should other reviews provide more comprehensive

[1] See Appendix II for more detailed, exhaustive search terms, with results per each database.

or up to date information. For example, two additional papers were added with Low and Critically Low rating of AMSTAR-II as they offered evidence on behaviour activation (Xu et al. 2020) and respite care (Walter et al. 2020) that were not included in other reviews. The selection process was transparently reported, with justification of choices.

2.3. Data collection and analysis

As the first stage in selecting relevant studies, records retrieved from the bibliographic databases and from other sources (such as snowballing and expert recommendations) were recorded and assessed for eligibility by examining their titles and abstracts only using COVIDENCE by two researchers independently. This assessment was performed in accordance with the inclusion and exclusion criteria developed above. The full text of articles found to be potentially relevant on the basis of their titles and abstracts were then retrieved and examined in light of the eligibility criteria in the second stage of study selection. Data from eligible studies were extracted into pre-defined templates that generally included the characteristics of the study design and of the population, intervention, comparator, and outcomes.

To ensure accuracy, two people independently assessed the eligibility of the studies identified and extracted data from study reports. Any inconsistencies between the two researchers were discussed as a team and consensus was reached. The lead researcher provided guidance throughout and acted as a final decision maker if consensus could not be reached.

The search strategy and results were carefully documented. This involved reporting the databases searched, the strategy used to search each database, the total number of citations retrieved from each database, and the reasons for having excluded some publications after reviewing the full text.

The flow of articles throughout the search and up to the final cohort of included studies were depicted with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram, which included the number of excluded articles and the reasons for any exclusions at the full-text screening stage.

2.4. Selection and coding of identified records

We used COVIDENCE and EndNote X.9.3.3 to organize all searched papers and remove duplicates the records obtained from the searches, with search outputs for each database before duplications are removed. A copy of the reference library in electronic format (without attached pdfs of included publications) is supplied alongside the final report.

2.5. Quality assessment

The AMSTAR-II[2] was used to assess the quality of included systematic reviews. This assessment was carried out by the two researchers independently and consensus was reached after discussion of any discrepancies found between the researchers. The lead researcher provided guidance throughout. See a supplementary file containing all AMSTAR rated studies, containing two researchers' rating and final decision.

2.6. Analysis of subgroups or subsets

Data synthesis was carried out based on 10 identified interventions:

- Psychoeducation
- Counselling and psychotherapy (including CBT)
- Mindfulness-based interventions and complementary and alternative medicine (CAM)
- Support groups, emotional support, social support
- Care coordination and case management
- Training of the care-recipient with caregiver involvement

[2] https://amstar.ca/Amstar_Checklist.php

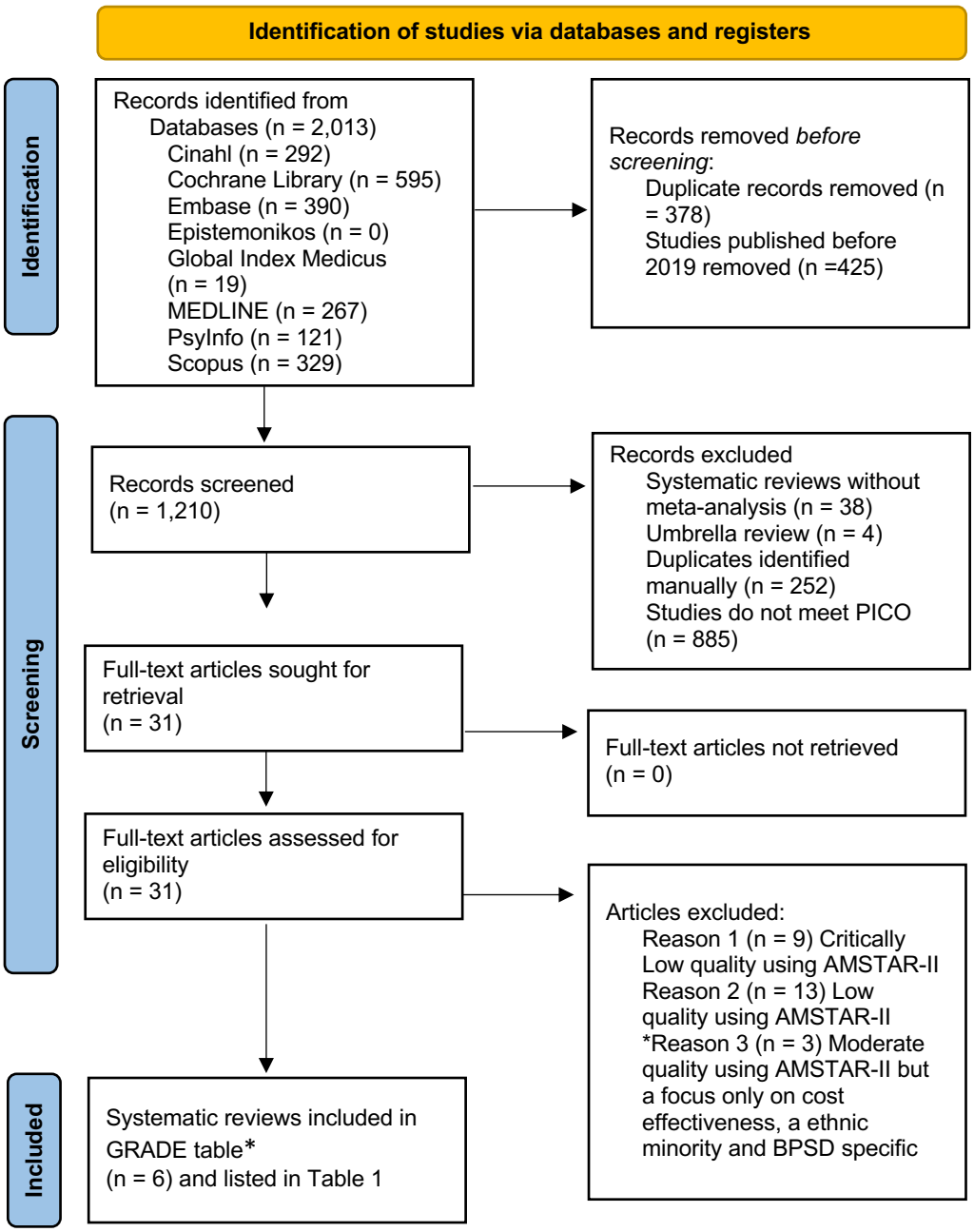
- Multicomponent Interventions
- Remotely delivered interventions
- Behavioural activation
- Respite

We considered the subgroups or subsets (different intervention / comparison groups), that were available in the included meta-analyses.
We included a narrative description of the reviews included in the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) table. This section included a report of the abstract of included reviews taken directly from the publications. Completed Grading of the evidence was represented in tables. Additional evidence not mentioned in GRADE tables was detailed in a narrative summary. We completed a summary of findings table that summarizes the GRADE table(s). For the evidence to decision table, we populated sections on priority of the problem, desirable effects, undesirable effects, certainty of evidence, and balance of effects.

3. Results

3.1. List of systematic reviews and/or studies identified by the search process

Figure 1: PRISMA 2020 flow diagram for systematic review of reviews which includes searches of databases and registers only



*Three papers were not included in the final GRADE table and detailed in a narrative summary instead.

3.1.1. Included in GRADE tables/footnotes

Cheng, S. T., Li, K. K., Losada, A., Zhang, F., Au, A., Thompson, L. W., & Gallagher-Thompson, D. (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: An updated systematic review and meta-analysis. *Psychology and Aging, 35(1)*, 55-77. doi:http://dx.doi.org/10.1037/pag0000401 **AMSTAR-II Moderate**

Gonzalez-Fraile, E., Ballesteros, J., Rueda, J.-R., Santos-Zorrozua, B., Sola, I., & McCleery, J. (2021). Remotely delivered information, training and support for informal caregivers of people with dementia. *Cochrane Database of Systematic Reviews*(1). **AMSTAR-II High**

Lee, M., Ryoo, J. H., Chung, M., Anderson, J. G., Rose, K., & Williams, I. C. (2020). Effective interventions for depressive symptoms among caregivers of people with dementia: A systematic review and meta-analysis. *Dementia (London, England), 19(7)*, 2368-2398. doi:http://dx.doi.org/10.1177/1471301218822640 **AMSTAR-II Moderate**

Lee, M., Ryoo, J. H., Crowder, J., Byon, H. D., & Wiiliams, I. C. (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. *Journal of Advanced Nursing, 76(2)*, 475-489. doi:http://dx.doi.org/10.1111/jan.14262 **AMSTAR-II Moderate**

Walter, E., & Pinquart, M. (2020). How Effective Are Dementia Caregiver Interventions? An Updated Comprehensive Meta-Analysis. *The Gerontologist, 60(8)*, 609-619. doi:https://dx.doi.org/10.1093/geront/gnz118 **AMSTAR-II Critically low**

Xu, X. Y., Kwan, R. Y. C., & Leung, A. Y. M. (2020). Behavioural activation for family dementia caregivers: A systematic review and meta-analysis. *Geriatric nursing (New York, N.Y.), 41(5)*, 544-552. doi:https://dx.doi.org/10.1016/j.gerinurse.2020.02.003 **AMSTAR-II Low**

3.1.2. Excluded from GRADE tables/footnotes

Akarsu, N. E., Prince, M. J., Lawrence, V. C., & Das-Munshi, J. (2019). Depression in carers of people with dementia from a minority ethnic background: Systematic review and meta-analysis of randomized controlled trials of psychosocial interventions. International Journal of Geriatric Psychiatry, 34(6), 790-806. doi:http://dx.doi.org/10.1002/gps.5070 **AMSTAR-II Moderate**

Huo, Z., Chan, J. Y. C., Lin, J., Bat, B. K. K., Chan, T. K., Tsoi, K. K. F., & Yip, B. H. K. (2021). Supporting Informal Caregivers of People With Dementia in Cost-Effective Ways: A Systematic Review and Meta-Analysis. Value in Health, 24(12), 1853-1862. doi:https://dx.doi.org/10.1016/j.jval.2021.05.011 **AMSTAR-II Moderate**

Meng, X., Su, J., Li, H., Ma, D., Zhao, Y., Li, Y., . . . Sun, J. (2021). Effectiveness of caregiver non-pharmacological interventions for behavioural and psychological symptoms of dementia: An updated meta-analysis. Ageing Research Reviews, 71 (no pagination). doi:http://dx.doi.org/10.1016/j.arr.2021.101448 **AMSTAR-II Moderate**

3.1.3. PICO Table

Table 1. PICO Table

Serial Number	Intervention/ Comparison	Outcomes	Systematic reviews (Name, Year)	Justification/Explanation for selection of systematic review
1	Psychoeducation* / nil treatment, minimal support, usual care, OR active control	Depressive symptoms- psychoeducation A & B	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of two types of psychoeducation on depressive symptoms in carers of people living with dementia.
		Carer burden and stress- psychoeducation A & B	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of two types of psychoeducation on burden and stress in carers of people living with dementia.
		Subjective well-being- psychoeducation A & B	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of two types of psychoeducation on subjective well-being in carers of people living with dementia.
		Health-related quality of life	Lee et al. 2019	Most recent moderate-quality meta-analysis available on the effectiveness of psychoeducation on health-related quality of life (HRQOL) in carers of people living with dementia.
		Anxiety - psychoeducation A & B	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of two types of psychoeducation on anxiety in carers of people living with dementia.
		Measures of ability, knowledge, skills, mastery- psychoeducation A & B	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of two types of psychoeducation on depressive symptoms carers of in people living with dementia.
		Positive aspects of caregiving - psychoeducation A & B	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of two types of psychoeducation on positive aspects of care giving in carers of people living with dementia.
		Social Support - psychoeducation A &B	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of two types of psychoeducation on social support in carers of people living with dementia.
2	Counselling and psychotherapy	Depressive symptoms	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of counselling and psychotherapy on depressive symptoms in carers of people living with dementia.

Serial Number	Intervention/ Comparison	Outcomes	Systematic reviews (Name, Year)	Justification/Explanation for selection of systematic review
	(including CBT) / nil treatment, minimal support, usual care OR active control	Carer burden and stress	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of counselling and psychotherapy on burden and stress in carers of people living with dementia.
		Subjective well-being	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of counselling and psychotherapy on subjective well-being in carers of people living with dementia.
		Health-related quality of life	Lee et al. 2019	Most recent moderate-quality meta-analysis available on the effectiveness of counselling and psychotherapy on HRQOL in carers of people living with dementia.
		Anxiety	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of counselling and psychotherapy on anxiety in carers of people living with dementia.
		Measures of ability, knowledge, skills, mastery	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of counselling and psychotherapy on measures of ability, knowledge, skills, mastery in carers of people living with dementia.
		Physical Health	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of counselling and psychotherapy on physical health in carers of people living with dementia.
3	Mindfulness-based interventions and complementary and alternative medicine (CAM) / nil treatment, minimal support, usual care OR active control	Depressive symptoms	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of mindfulness-based interventions and CAM on depressive symptoms in carers of people living with dementia.
		Carer burden and stress	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of mindfulness-based interventions and CAM on burden and stress in carers of people living with dementia.
		Subjective well-being	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of mindfulness-based interventions and CAM on subjective well-being in carers of people living with dementia.
		Health-related quality of life	Lee et al. 2019	Most recent moderate-quality meta-analysis available on the effectiveness of mindfulness-based interventions and CAM on HRQOL in carers of people living with dementia.
		Anxiety	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of mindfulness-based interventions andCAM) on anxiety in carers of people living with dementia.
		Measures of ability, knowledge, skills, mastery	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of mindfulness-based interventions and CAM on measures of ability, knowledge, skills, mastery in carers of people living with dementia.

Serial Number	Intervention/ Comparison	Outcomes	Systematic reviews (Name, Year)	Justification/Explanation for selection of systematic review
		Social Support	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of mindfulness-based interventions and CAM on social support in carers of people living with dementia.
4	Support groups, emotional support, social support / nil treatment, minimal support, usual care OR active control	Depressive symptoms	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of support groups, emotional/social support on depressive symptoms in carers of people living with dementia.
		Carer burden and stress	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of support groups, emotional/social support on burden and stress in carers of people living with dementia.
		Subjective well-being	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of support groups, emotional/social support on subjective well-being in carers of people living with dementia
		Health-related quality of life	Lee et al. 2019	Most recent moderate-quality meta-analysis available on the effectiveness of support groups, emotional/social support on HRQOL in carers of people living with dementia.
		Anxiety	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of support groups, emotional/social support on anxiety in carers of people living with dementia.
		Positive aspects of caregiving	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of support groups, emotional/social support on positive aspects of caregiving in carers of people living with dementia.
		Social Support	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of support groups, emotional/social support on social support in carers of people living with dementia.
5	Care coordination and case management / nil treatment, minimal support, usual care OR active control	Depressive symptoms	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of care coordination and case management on depressive symptoms in carers of people living with dementia.
		Carer burden and stress	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of care coordination and case management on burden and stress in carers of people living with dementia.
		Subjective well-being	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of care coordination and case management on subjective well-being in carers of people living with dementia.

Serial Number	Intervention/ Comparison	Outcomes	Systematic reviews (Name, Year)	Justification/Explanation for selection of systematic review
		Health-related quality of life	Lee et al. 2019	Most recent moderate-quality meta-analysis available on the effectiveness of care coordination and case management on HRQOL in carers of people living with dementia.
		Anxiety	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of care coordination and case management on anxiety in carers of people living with dementia.
		Measures of ability, knowledge, skills, mastery	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of care coordination and case management on measures of ability, knowledge, skills, mastery in carers of people living with dementia.
		Physical health	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of care coordination and case management on physical health in carers of people living with dementia.
		Social Support	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of care coordination and case management on social support in carers of people living with dementia.
6	Training of the care-recipient caregiver involvement / nil treatment, minimal support, usual care OR active control	Depressive symptoms	Lee et al. 2020 Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of training of the care-recipient with caregiver involvement on depressive symptoms. Two types: Cheng et al. 2020 (Training of the care recipient with direct carer involvement, such as reminiscence, cognitive stimulation, occupational therapy, exercise); Lee et al. 2020 (Cognitive rehabilitation for people living with dementia).
		Carer burden and stress	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of training of care recipients with carer involvement on burden and stress in carers of people living with dementia.
		Subjective well-being	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of training of care recipients with carer involvement on subjective well-being in carers of people living with dementia.
		Health related quality of life	Lee et al. 2019	Most recent moderate-quality meta-analysis available on the effectiveness of training of care recipients with carer involvement on HR-QoL in carers of people living with dementia.
		Anxiety	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of training of care recipients with carer involvement on anxiety in carers of people living with dementia.

Serial Number	Intervention/ Comparison	Outcomes	Systematic reviews (Name, Year)	Justification/Explanation for selection of systematic review
		Measures of ability, knowledge, skills, mastery	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of training of care recipients with carer involvement on measures of ability, knowledge, skills, mastery in carers of people living with dementia.
7	Multicomponent Interventions / nil treatment, minimal support, usual care OR active control	Depressive symptoms	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on depressive symptoms in carers of people living with dementia.
		Carer burden and stress	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on burden and stress in carers of people living with dementia.
		Subjective well-being	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on subjective well-being in carers of people living with dementia.
		Health-related quality of life	Lee et al. 2019	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on HRQOL in carers of people living with dementia.
		Anxiety	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on anxiety in carers of people living with dementia.
		Measures of ability, knowledge, skills, mastery	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on measures of ability, knowledge, skills, mastery in carers of people living with dementia.
		Positive aspects of caregiving	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on positive aspects of caregiving in carers of people living with dementia.
		Physical health	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on physical health in carers of people living with dementia.
		Social support	Cheng et al. 2020	Most recent moderate-quality meta-analysis available on the effectiveness of multicomponent interventions on social support in carers of people living with dementia.

Serial Number	Intervention/ Comparison	Outcomes	Systematic reviews (Name, Year)	Justification/Explanation for selection of systematic review
8	Remotely Delivered Interventions (carer training, support or both) / Control Group 1 (usual treatment, wait-list or attention control) and Control Group 2 (information only)	Depressive symptoms	Gonzales-Fraile et al. 2021	Most recent high-quality meta-analysis available on the effectiveness of remotely delivered interventions on depressive symptoms in carers of people living with dementia.
		Carer burden	Gonzales-Fraile et al. 2021	Most recent high-quality meta-analysis available on the effectiveness of remotely delivered interventions on burden in carers of people living with dementia.
		Health-related quality of life	Gonzales-Fraile et al. 2021	Most recent high-quality meta-analysis available on the effectiveness of remotely delivered interventions on depressive symptoms in carers of people living with dementia.
		Carer knowledge and skills	Gonzales-Fraile et al. 2021	Most recent high-quality meta-analysis available on the effectiveness of remotely delivered interventions on carer knowledge and skills in carers of people living with dementia.
		Use of health and social care resources	Gonzales-Fraile et al. 2021	Most recent high-quality meta-analysis available on the effectiveness of remotely delivered interventions on use of health and social care resources in carers of people living with dementia.
		Admission of person with dementia to institutional care	Gonzales-Fraile et al. 2021	Most recent high-quality meta-analysis available on the effectiveness of remotely delivered interventions on care recipient institutionalization in carers of people living with dementia.
		Dropouts for any reason (acceptability)	Gonzales-Fraile et al. 2021	Most recent high-quality meta-analysis available on the effectiveness of remotely delivered interventions on acceptability of the intervention in carers of people living with dementia.
9	Respite / wait list control or minimal attention	Depressive symptoms	Walter et al. 2020	Most recent critically low-quality meta-analysis available on the effectiveness of respite on depressive symptoms in carers of people living with dementia. This review is the only review on the effectiveness of respite for carers published in Jan 2019-Jan 2022.
		Carer burden	Walter et al. 2020	Most recent critically low-quality meta-analysis available on the effectiveness of respite on burden in carers of people living with dementia. This review is the only review on the effectiveness of respite for carers published in Jan 2019-Jan 2022.
		Subjective well-being	Walter et al. 2020	Most recent critically low-quality meta-analysis available on the effectiveness of respite on subjective well-being in carers of people living with dementia. This review is the only review on the effectiveness of respite for carers published in Jan 2019-Jan 2022.
		Ability/knowledge	Walter et al. 2020	Most recent critically low-quality meta-analysis available on the effectiveness of respite on carer ability and knowledge in carers of people living with dementia. This review is the only review on the effectiveness of respite for carers published in Jan 2019-Jan 2022.

Serial Number	Intervention/ Comparison	Outcomes	Systematic reviews (Name, Year)	Justification/Explanation for selection of systematic review
		Anxiety	Walter et al. 2020	Most recent critically low-quality meta-analysis available on the effectiveness of respite on anxiety in carers of people living with dementia. This review is the only review on the effectiveness of respite for carers published in Jan 2019-Jan 2022.
		Care recipient Symptoms	Walter et al. 2020	Most recent critically low-quality meta-analysis available on the effectiveness of respite on care recipient symptoms in carers of people living with dementia. This review is the only review on the effectiveness of respite for carers published in Jan 2019-Jan 2022.
		Institutionalization	Walter et al. 2020	Most recent critically low-quality meta-analysis available on the effectiveness of respite on care recipient institutionalization in carers of people living with dementia. This review is the only review on the effectiveness of respite for carers published in Jan 2019-Jan 2022.
10	Behavioural activation / standard care; information support; materials, information packages, psychoeducation; home visits	Depressive symptoms	Xu et al. 2020	Most recent low-quality meta-analysis available on the effectiveness of behavioural activation on depressive symptoms in carers of people living with dementia. This review is the only review on the effectiveness of behavioural activation published in Jan 2019-Jan 2022.

*Psychoeducation: Cheng et al. (2022) divide psychoeducation into two types: Psychoeducation A (educational programs with *probable* psychological components to improve coping. These programs focus on increasing caregivers' knowledge of dementia and developing specific coping skills to deal with challenges in caregiving based largely on the stress-and-coping model.); and Psychoeducation B (educational programs with psychotherapeutic components such as cognitive–behavioural theories. Group psychotherapy would also be classified here if the therapeutic components are adapted for delivery in a structured psychoeducational format.). On the other hand, Lee et al. (2019) use psychoeducation in a broad term as an intervention that provides information on the dementia disease process and caregiving-related topics which may contain actions on applying learned knowledge to individual caregiving situations.

3.2. Narrative description of studies that contributed to GRADE analysis

Six index systematic reviews selected for the evidence review include:

- Cheng, S. T., Li, K. K., Losada, A., Zhang, F., Au, A., Thompson, L. W., & Gallagher-Thompson, D. (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: An updated systematic review and meta-analysis. *Psychology and Aging, 35(1)*, 55-77.

- Gonzalez-Fraile, E., Ballesteros, J., Rueda, J.-R., Santos-Zorrozua, B., Sola, I., & McCleery, J. (2021). Remotely delivered information, training and support for informal caregivers of people with dementia. *Cochrane Database of Systematic Reviews*(1).

- Lee, M., Ryoo, J. H., Chung, M., Anderson, J. G., Rose, K., & Williams, I. C. (2020). Effective interventions for depressive symptoms among caregivers of people with dementia: A systematic review and meta-analysis. *Dementia (London, England), 19(7)*, 2368-2398.

- Lee, M., Ryoo, J. H., Crowder, J., Byon, H. D., & Wiiliams, I. C. (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. *Journal of Advanced Nursing, 76(2)*, 475-489.

- Walter E, Pinquart M (2020). How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. Gerontologist, 60(8):e609-e619. DOI: 10.1093/geront/gnz118

- Xu, Kwan, Leung (2020). Behavioural activation for family dementia caregivers: a systematic review and meta-analysis. Geriatric Nursing, 41:544-552. DOI: 10.1016/j.gerinurse.2020.02.003

The six index systematic reviews were used to extract outcomes data on 10 interventions: i) psychoeducation; ii) counselling and psychotherapy (including CBT); iii) mindfulness-based interventions and CAM; iv) support groups, emotional support, social support; v) care coordination and case management; vi) training of the care-recipient with caregiver involvement; vii) multicomponent Interventions; viii) remotely delivered interventions; ix) behavioural activation; and x) respite.

Cheng et al. provided data on the effectiveness of interventions for outcomes of caregiver burden and stress, depressive symptoms, anxiety, subjective well-being, positive aspects of caregiving, physical health, social support and measures of ability, knowledge, skills, and mastery. Cheng et al. was able to pool data from 350 post-intervention effect sizes in 128 studies and 155 follow-up effect sizes in 55 studies.
Most studies included in this index systematic review were from North America and Europe. Mean intervention duration was four months and mean follow-up period was 6.5 months. Heterogeneous tools and psychometric scales were used for assessment of outcomes. This index systematic review found that educational programs (with psychotherapeutic components), counselling/psychotherapy, and mindfulness-based interventions had the strongest effects on reducing depressive symptoms. Multicomponent and miscellaneous

interventions had the largest effects on reduction of burden/stress. Multicomponent and mindfulness-based interventions had the largest effects on enhancing subjective well-being. Mindfulness and counselling/psychotherapy studies generally had small samples, and studies with smaller sample sizes tended to report larger effects. Overall, small-study effects were found in five out of seven outcomes at post-intervention and two out of four outcomes at follow-up. Small-study effects might have been due a number of factors such as selection bias (e.g. publication bias, selective reporting) or true heterogeneity (e.g. better-quality control in small studies, enrolment of at-risk individuals more likely to benefit from treatment). Cheng reported that risk of bias was high for blinding of participants/personnel and selective reporting.

Lee, M., Ryoo, J. H., Chung, M et al. (2020) provided data on effective interventions for depressive symptoms among caregivers of people with dementia. This systematic review was able to pool data from 31 randomized controlled studies (RCTs) (n=40389). The majority of the studies were conducted in the United States of America (n = 14), followed by the United Kingdom (n = 5). The intervention duration varied across the studies (8 to 16 weeks). Heterogeneous tools and psychometric scales were used for assessment of outcomes. This index systematic review found that cognitive-behavioural therapy interventions, which focus on diminishing negative thoughts and increasing positive activities, showed a large and significant effect in decreasing depressive symptoms for caregivers of individuals with dementia (standardized mean difference - 0.905; 95% CI -1.622, -0.187); p = 0.013)

Lee, M., Ryoo, J. H., Crowder, J., et al. (2019) provided data on effective interventions for health-related quality of life among caregivers of people with dementia. Lee was able to pool data from 26 studies (n= 3906). Most studies (n=14) were conducted in Europe. The average intervention duration varied significantly across the studies from 4-6 months to 1-2 years. This meta-analysis investigated the intervention effectiveness on global HRQOL scores rather than each sub-dimensional HRQOL score. A range of HRQOL instruments were included in the review (e.g. WHO Quality of Life-BREF [WHOQOL-BREF], Dementia Quality of Life, 12-Item Short Form Survey [SF-12], EQ-5D). This index systematic review reported that multicomponent interventions, CBT and complementary alternative medicine therapy showed significant effects on improving caregiver's health-related quality of life, while psychoeducation, social support, case management and cognitive rehabilitation therapy failed to produce significant effects.

Gonzalez-Fraile et al. (2021) provided data on the effectiveness of remotely delivered interventions for the outcomes on depressive symptoms and mood, carer burden, health related quality of life, use of health and social care resources, admission of person with dementia to institutional care, dropouts for any reason (acceptability) and measures of ability, knowledge, skills, and mastery. The systematic review pooled results from 26 studies (n=2367) and compared remote interventions involving training, support, or both with or without information (experimental interventions). Control was defined as usual treatment, waiting list or attention control (12 studies, 944 participants); and he provision of information alone (14 studies, 1423 participants). Most studies were from the United States of America (15 studies, 58%). China and the Netherlands contributed three studies each, France two studies, and Canada, Spain, and the United Kingdom one study each.
Studies had a median sample size of 67 participants (interquartile range (IQR) 49 to 110) and a median duration of 16 weeks (IQR 12 to 24). Studies used different measures with different metrics to report conceptually similar outcomes, therefore the standardized mean difference (SMD) for continuous outcomes as the measure of effect size was reported. The systematic review found that the experimental interventions probably have little or no effect on caregiver

burden (9 studies, 597 participants; SMD -0.06, 95% confidence interval (CI) -0.35 to 0.23); depressive symptoms (eight studies, 638 participants; SMD -0.05, 95% CI -0.22 to 0.12); or health-related quality of life (2 studies, 311 participants; SMD 0.10, 95% CI -0.13 to 0.32). The experimental interventions probably result in little or no difference in dropout for any reason (8 studies, 661 participants; risk ratio [RR] 1.15, 95% CI 0.87 to 1.53).

Walter E, Pinquart M (2020) updated the meta-analysis conducted by Pinquart and Sörensen (2006). Based on a systematic search in electronic data bases, effects of 282 controlled studies were integrated. This index systematic review provided data on effectiveness of respite interventions for outcomes depressive symptoms and mood, carer burden, subjective well-being, anxiety, care recipient symptoms, institutionalization, and measures of ability, knowledge, skills, mastery. Respite interventions were described in 24 studies. Respite improved burden and anxiety, with small, immediate effect size at post-test.
Although there was no evidence for efficacy of respite interventions at follow-up.

Xu, Kwan, Leung (2020) provided data on the effectiveness of behavioural activation (BA) for family dementia caregivers on depressive symptoms. The systematic review pooled data from 10 randomized controlled trials (n=895). Studies were conducted in China, Spain, Japan, the Netherlands and the United States of America. Heterogeneity of the intervention protocols used in these studies was a concern in terms of their duration, the content and format of the BA intervention, the emphasis of the intervention. The studies used a variety of measures to evaluate depression, in seven studies the Center for Epidemiologic Studies Depression Scale (CES-D) was used, in one study the Beck Depression Inventory-II (BDI-II) was used, and in one study the BDI was used. All of the studies were considered to be at low risk of selection bias. Depression was significantly reduced after participants received BA (n = 9; 786 participants; SMD = -0.69; 95% CI: -1.12 to -0.25; p = 0.002)

3.3. Grading the Evidence

Table 2. Psychoeducation vs nil treatment, minimal support, usual care OR active control

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are psychoeducation interventions effective for improving their outcomes?
Setting: Community
Reference List:
Cheng, Li, Losada, Zhang, Au, Thompson, Gallagher-Thompson (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. Psychology and Aging, 35(1):55-77. DOI: 10.1037/pag0000401

Lee, Ryoo, Crowder, Byon, Williams (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. Journal of Advanced Nursing, 76:475-489. DOI: 10.1111/jan.14262

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depression (higher scores indicate more severe depressive symptoms) - Psychoeducation A (Cheng et al. 2020)												
12	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[7]	1374	0[7]	Hedges' g -0.19 (-0.29, -0.08)		⨁⨁◯◯ Low	Critical
Depression (higher scores indicate more severe depressive symptoms) - Psychoeducation B (Cheng et al. 2020)												
18	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	Publication bias[7]	1737	0[7]	Hedges' g -0.37 (-0.52, -0.23)		⨁◯◯◯ Very low	Critical I

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Carer burden and stress (higher scores indicate more carer burden and stress) - Psychoeducation A (Cheng et al. 2020)												
20	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	Publication bias[6]	1728	0[7]	Hedges' g -0.23 (-0.39, -0.07)		⨁◯◯◯ Very low	Critical
Carer burden and stress (higher scores indicate more carer burden and stress) - Psychoeducation B (Cheng et al. 2020)												
17	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	Publication bias[6]	1694	0[7]	Hedges' g -0.23 (-0.37, -0.08)		⨁◯◯◯ Very low	Critical
Subjective well-being (higher scores indicate better subjective well-being) - Psychoeducation A (Cheng et al. 2020)												
15	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[6]	1603	0[7]	Hedges' g 0.20 (0.05, 0.34)		⨁⨁◯◯ Low	Critical
Subjective well-being (higher scores indicate better subjective well-being) - Psychoeducation B (Cheng et al. 2020)												
10	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[6]	1036	0[7]	Hedges' g 0.20 (0.05, 0.35)		⨁⨁◯◯ Low	Critical
Health-related quality of life (higher scores indicate better health-related quality of life) – Psychoeducation C (Lee et al. 2019)												
5	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	390	326	Hedges' g 0.163 (-0.001, 0.328)		⨁◯◯◯ Very low	Critical
Measures of ability, knowledge, skills, mastery (higher scores indicate better ability, knowledge, skills, mastery) - Psychoeducation A (Cheng et al. 2020)												
12	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[6]	1060	0[7]	Hedges' g 0.20 (0.07, 0.32)		⨁⨁◯◯ Low	Critical

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Measures of ability, knowledge, skills, mastery (higher scores indicate better ability, knowledge, skills, mastery) - Psychoeducation B (Cheng et al. 2020)												
9	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[6]	833	0[7]	Hedges' g 0.32 (0.18, 0.46)		⨁⨁◯◯ Low	Critical
Anxiety (higher scores indicate worse anxiety) - Psychoeducation A (Cheng et al. 2020)												
4	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias[6]	380	0[7]	Hedges' g -0.15 (-0.54, 0.24)		⨁◯◯◯ Very low	Critical
Anxiety (higher scores indicate worse anxiety) - Psychoeducation B (Cheng et al. 2020)												
6	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias[6]	635	0[7]	Hedges' g -0.20 (-0.64, 0.23)		⨁◯◯◯ Very low	Critical
Positive aspects of caregiving (higher scores indicate more positive aspects of caregiving) - Psychoeducation A (Cheng et al. 2020)												
2	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias[6]	322	0[7]	Hedges' g 0.28 (-0.84, 1.40)		⨁◯◯◯ Very low	Important
Positive aspects of caregiving (higher scores indicate more positive aspects of caregiving) - Psychoeducation B (Cheng et al. 2020)												
4	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	Publication bias[6]	347	0[7]	Hedges' g 0.82 (0.22, 1.41)		⨁◯◯◯ Very low	Important
Social support (higher scores indicate better social support) - Psychoeducation A (Cheng et al. 2020)												
1	RCT	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	36	0[7]	Hedges' g 0.42 (-0.25, 1.08)		⨁◯◯◯ Very low	Important

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Social support (higher scores indicate better social support) - Psychoeducation B (Cheng et al. 2020)												
1	RCT	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	111	0[7]	Hedges' g 0.19 (-0.27, 0.65)		⨁◯◯◯ Very low	Important

CI: confidence interval; RCTs: randomized controlled trials

Psychoeducation A (educational programs with *probable* psychological components to improve coping. These programs focus on increasing caregivers' knowledge of dementia and developing specific coping skills to deal with challenges in caregiving based largely on the stress-and-coping model) (Cheng et al. 2020)

Psychoeducation B (educational programs with psychotherapeutic components such as cognitive–behavioural theories. Group psychotherapy would also be classified here if the therapeutic components are adapted for delivery in a structured psychoeducational format) (Cheng et al. 2020)

Psychoeducation C (educational programs that provide standardized information about dementia, stress management, communication skills and handling of care recipients' distressed behaviours) Lee et al. (2019)

[1] 4 categories of quality of evidence: ⨁⨁⨁⨁ (High), ⨁⨁⨁◯ (Moderate), ⨁⨁◯◯ (Low), ⨁◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the Cochrane risk-of-bias tool for randomized trials (ROB) decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.

[5] Small sample size and CI around magnitude of effect

[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.

[7] Not reported.

Table 3. Counselling and psychotherapy (including CBT) vs nil treatment, minimal support, usual care OR active control

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are counselling and psychotherapy (including CBT) interventions effective for improving their outcomes?
Setting: Community
Reference List:

Cheng, Li, Losada, Zhang, Au, Thompson, Gallagher-Thompson (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. Psychology and Aging, 35(1):55-77. DOI: 10.1037/pag0000401

Lee, Ryoo, Crowder, Byon, Williams (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. Journal of Advanced Nursing, 76:475-489. DOI: 10.1111/jan.14262

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depression (higher scores indicate more severe depressive symptoms) (Cheng et al. 2020)												
9	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	Publication bias [6]	996	0 [7]	Hedges' g -0.35 (-0.55, -0.15)		⨁◯◯◯ Very low	Critical
Carer burden and stress (higher scores indicate more severe carer burden and stress) (Cheng et al. 2020)												
6	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	657	0 [7]	Hedges' g -0.12 (-0.28, 0.03)		⨁◯◯◯ Very low	Critical
Subjective well-being (higher scores indicate better subjective well-being) (Cheng et al. 2020)												

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
4	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	587	0[7]	Hedges' g 0.17 (-0.06, 0.40)		⨁◯◯◯ Very low	Critical
Health-related quality of life (higher scores indicate better health-related quality of life) (Lee et al. 2019)												
3	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias[6]	229	136	Hedges' g 0.767 (0.142, 1.391)		⨁◯◯◯ Very low	Critical
Anxiety (higher scores indicate worse anxiety) (Cheng et al. 2020)												
3	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	No serious imprecision[c]	Publication bias[6]	394	0[7]	Hedges' g -0.25 (-0.47, -0.03)		⨁⨁◯◯ Low	Critical
Measures of ability, knowledge, skills, mastery (higher scores indicate better ability, knowledge, skills, mastery) (Cheng et al. 2020)												
3	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	354	0[7]	Hedges' g 0.17 (-0.05, 0.38)		⨁◯◯◯ Very low	Critical
Physical health (higher scores indicate better physical health) (Cheng et al. 2020)												
1	RCT	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	273	0[7]	Hedges' g 0.14 (-0.10, 0.38)		⨁◯◯◯ Very low	Important

CI: confidence interval; RCTs: randomized controlled trials

[1] 4 categories of quality of evidence: ⨁⨁⨁⨁ (High), ⨁⨁⨁◯ (Moderate), ⨁⨁◯◯ (Low), ⨁◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the ROB decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.

[5] Small sample size and CI around magnitude of effect

[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.[7] Not reported.

Table 4. Mindfulness-based interventions and complementary and alternative medicine (CAM) vs nil treatment, minimal support, usual care OR active control

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are mindfulness-based interventions and complementary and alternative medicine (CAM) interventions effective for improving their outcomes?
Setting: Community
Reference List:
Cheng, Li, Losada, Zhang, Au, Thompson, Gallagher-Thompson (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. Psychology and Aging, 35(1):55-77. DOI: 10.1037/pag0000401

Lee, Ryoo, Crowder, Byon, Williams (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. Journal of Advanced Nursing, 76:475-489. DOI: 10.1111/jan.14262

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depression (higher scores indicate more severe depressive symptoms) (Cheng et al. 2020)												
7	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	258	0 [7]	Hedges' g -0.58 (-0.83, -0.33)		⨁◯◯◯ Very low	Critical
Carer burden and stress (higher scores indicate more severe carer burden and stress) (Cheng et al. 2020)												
4	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	142	0 [7]	Hedges' g -0.20 (-0.57, 0.18)		⨁◯◯◯ Very low	Critical
Subjective well-being (higher scores indicate better subjective well-being) (Cheng et al. 2020)												

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
6	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	212	0[7]	Hedges' g 0.31 (0.03, 0.58)		⊕◯◯◯ Very low	Critical
Health-related quality of life (higher scores indicate better health-related quality of life) (Lee et al. 2019)												
2	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	45	39	Hedges' g 0.576 (0.035, 1.118)		⊕◯◯◯ Very low	Critical
Anxiety (higher scores indicate worse anxiety) (Cheng et al. 2020)												
3	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias[6]	135	0[7]	Hedges' g -0.65 (-1.51, 0.21)		⊕◯◯◯ Very low	Critical
Measures of ability, knowledge, skills, mastery (higher scores indicate better ability, knowledge, skills, mastery) (Cheng et al. 2020)												
3	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	67	0[7]	Hedges' g 0.02 (-0.47, 0.50)		⊕◯◯◯ Very low	Critical
Social support (higher scores indicate better social support) (Cheng et al. 2020)												
1	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	72	0[7]	Hedges' g 0.24 (-0.22, 0.71)		⊕◯◯◯ Very low	Important

CI: confidence interval; RCTs: randomized controlled trials

[1] 4 categories of quality of evidence: ⊕⊕⊕⊕ (High), ⊕⊕⊕◯ (Moderate), ⊕⊕◯◯ (Low), ⊕◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the ROB decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.[5] Small sample size and CI around magnitude of effect

[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.[7] Not reported.

Table 5. Support groups, emotional support, social support vs nil treatment, minimal support, usual care OR active control

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are support groups, emotional support, social support interventions effective for improving their outcomes?
Setting: Community
Reference List:

Cheng, Li, Losada, Zhang, Au, Thompson, Gallagher-Thompson (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. Psychology and Aging, 35(1):55-77. DOI: 10.1037/pag0000401

Lee, Ryoo, Crowder, Byon, Williams (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. Journal of Advanced Nursing, 76:475-489. DOI: 10.1111/jan.14262

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depression (higher scores indicate more severe depressive symptoms) (Cheng et al. 2020)												
3	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias [6]	474	0 [7]	Hedges' g -0.11 (-0.40, 0.19)		⨁◯◯◯ Very low	Critical
Carer burden and stress (higher scores indicate more severe carer burden and stress) (Cheng et al. 2020)												
4	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias [6]	415	0 [7]	Hedges' g -0.20 (-0.55, 0.15)		⨁◯◯◯ Very low	Critical
Subjective well-being (higher scores indicate better subjective well-being) (Cheng et al. 2020)												
4	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias [6]	526	0 [7]	Hedges' g 0.62 (-0.26, 1.50)		⨁◯◯◯ Very low	Critical

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Health-related quality of life (higher scores indicate better health-related quality of life) (Lee et al. 2019)												
3	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias [6]	230	227	Hedges' g 0.231 (-0.104, 0.567)		⊕◯◯◯ Very low	Critical
Anxiety (higher scores indicate worse anxiety) (Cheng et al. 2020)												
1	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	217	0 [7]	Hedges' g -0.05 (-0.32, 0.22)		⊕◯◯◯ Very low	Critical
Positive aspects of caregiving (higher scores indicate more positive aspects of caregiving) (Cheng et al. 2020)												
1	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	103	0 [7]	Hedges' g 0.19 (-0.20, 0.58)		⊕◯◯◯ Very low	Important
Social support (higher scores indicate better social support) (Cheng et al. 2020)												
2	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias [6]	295	0 [7]	Hedges' g 0.23 (-0.27, 0.74)		⊕◯◯◯ Very low	Important

CI: confidence interval; RCTs: randomized controlled trials[1] 4 categories of quality of evidence: ⊕⊕⊕⊕ (High), ⊕⊕⊕◯ (Moderate), ⊕⊕◯◯ (Low), ⊕◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the ROB decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.

[5] Small sample size and CI around magnitude of effect

[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.

[7] Not reported.

Table 6. Care coordination and case management vs nil treatment, minimal support, usual care OR active control

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are care coordination and case management interventions effective for improving their outcomes?
Setting: Community
Reference List:

Cheng, Li, Losada, Zhang, Au, Thompson, Gallagher-Thompson (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. Psychology and Aging, 35(1):55-77. DOI: 10.1037/pag0000401

Lee, Ryoo, Crowder, Byon, Williams (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. Journal of Advanced Nursing, 76:475-489. DOI: 10.1111/jan.14262

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depression (higher scores indicate more severe depressive symptoms) (Cheng et al. 2020)												
6	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	808	0[7]	Hedges' g -0.07 (-0.24, 0.10)		⨁◯◯◯ Very low	Critical
Carer burden and stress (higher scores indicate more severe carer burden and stress) (Cheng et al. 2020)												
12	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[6]	1855	0[7]	Hedges' g -0.15 (-0.26, -0.04)		⨁⨁◯◯ Low	Critical
Subjective well-being (higher scores indicate better subjective well-being) (Cheng et al. 2020)												
7	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias[6]	1112	0[7]	Hedges' g 0.18 (-0.03, 0.39)		⨁◯◯◯ Very low	Critical

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Health-related quality of life (higher scores indicate better health-related quality of life) (Lee et al. 2019)												
3	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	444	444	Hedges' g 0.135 (-0.076, 0.346)		⊕◯◯◯ Very low	Critical
Anxiety (higher scores indicate worse anxiety) (Cheng et al. 2020)												
1	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	46	0 [7]	Hedges' g -0.28 (-0.73, 0.16)		⊕◯◯◯ Very low	Critical
Measures of ability, knowledge, skills, mastery (higher scores indicate better ability, knowledge, skills, mastery) (Cheng et al. 2020)												
5	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias [6]	541	0 [7]	Hedges' g 0.08 (-0.19, 0.35)		⊕◯◯◯ Very low	Critical
Physical health (higher scores indicate better physical health) (Cheng et al. 2020)												
1	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	84	0 [7]	Hedges' g -0.05 (-0.50, 0.40)		⊕◯◯◯ Very low	Important
Social support (higher scores indicate better social support) (Cheng et al. 2020)												
3	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias [6]	541	0 [7]	Hedges' g 0.04 (-0.13, 0.21)		⊕◯◯◯ Very low	Important

CI: confidence interval; RCTs: randomized controlled trials

[1] 4 categories of quality of evidence: ⊕⊕⊕⊕ (High), ⊕⊕⊕◯ (Moderate), ⊕⊕◯◯ (Low), ⊕◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the ROB decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.
[5] Small sample size and CI around magnitude of effect
[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.
[7] Not reported.

Table 7. Training of the care-recipient (CR) with caregiver involvement vs nil treatment, minimal support, usual care OR active control

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are training of the care-recipient (CR) with caregiver involvement interventions effective for improving their outcomes?
Setting: Community
Reference List:

Cheng, Li, Losada, Zhang, Au, Thompson, Gallagher-Thompson (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. Psychology and Aging, 35(1):55-77. DOI: 10.1037/pag0000401

Lee, Ryoo, Chung, Anderson, Rose, Williams (2020). Effective interventions for depressive symptoms among caregivers of people with dementia: a systematic review and meta-analysis. Dementia, 19(7):2368-2398. DOI: 10.1177/1471301218822640

Lee, Ryoo, Crowder, Byon, Williams (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. Journal of Advanced Nursing, 76:475-489. DOI: 10.1111/jan.14262

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depressive symptoms (higher scores indicate more severe depressive symptoms) - Training of the care recipient (Cheng et al. 2020)												
9	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	Publication bias[6]	1250	0[7]	Hedges' g -0.24 (-0.46, -0.01)		⨁◯◯◯ Very low	Critical
Depressive symptoms (higher scores indicate more severe depressive symptoms) - Cognitive rehabilitation (Lee et al. 2020)												

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
5	RCTs	No serious risk of bias	No serious inconsistency	No serious indirectness	No serious imprecision	None	933	0[7]	SMD -0.104 (-0.240, 0.031)		⨁⨁⨁⨁ High	Critical
Carer burden and stress (higher scores indicate more severe carer burden and stress) - Training of the care recipient (Cheng et al. 2020)												
11	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	1528	0[7]	Hedges' g -0.12 (-0.28, 0.04)		⨁◯◯◯ Very low	Critical
Subjective well-being (higher scores indicate better subjective well-being) - Training of the care recipient (Cheng et al. 2020)												
8	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias[6]	1077	0[7]	Hedges' g 0.29 (-0.01, 0.58)		⨁◯◯◯ Very low	Critical
Health-related quality of life (higher scores indicate better health-related quality of life) Cognitive rehabilitation (Lee et al. 2019)												
2	RCTs	No serious risk of bias	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	203	199	Hedges' g 0.010 (-0.208, 0.229)		⨁⨁◯◯ Low	Critical
Anxiety (higher scores indicate worse anxiety) - Training of the care recipient (Cheng et al. 2020)												
3	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	718	0[7]	Hedges' g -0.06 (-0.21, 0.09)		⨁⨁◯◯ Low	Critical
Measures of ability, knowledge, skills, mastery (higher scores indicate better ability, knowledge, skills, mastery) - Training of the care recipient (Cheng et al. 2020)												

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
7	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	None	754	0 [7]	Hedges' g 0.52 (0.09, 0.95)		⨁⨁◯◯ Low	Critical

CI: confidence interval; RCTs: randomized controlled trials

Cheng et al. 2020 (Training of the care recipient with direct carer involvement, such as reminiscence, cognitive stimulation, occupational therapy, exercise)

Lee et al. 2019 & 2020 (Cognitive rehabilitation for people living with dementia, designed to improve or maintain care recipient competence using strategies designed to strengthen cognition)

[1] 4 categories of quality of evidence: ⨁⨁⨁⨁ (High), ⨁⨁⨁◯ (Moderate), ⨁⨁◯◯ (Low), ⨁◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the ROB decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.

[5] Small sample size and CI around magnitude of effect

[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.

[7] Not reported.

Table 8. Multicomponent Interventions vs nil treatment, minimal support, usual care OR active control

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are multicomponent interventions effective for improving their outcomes?
Setting: Community
Reference List:

Cheng, Li, Losada, Zhang, Au, Thompson, Gallagher-Thompson (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: an updated systematic review and meta-analysis. Psychology and Aging, 35(1):55-77. DOI: 10.1037/pag0000401

Lee, Ryoo, Crowder, Byon, Williams (2019). A systematic review and meta-analysis on effective interventions for health-related quality of life among caregivers of people with dementia. Journal of Advanced Nursing, 76:475-489. DOI: 10.1111/jan.14262

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depression (higher scores indicate more severe depressive symptoms) (Cheng et al. 2020)												
12	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	Publication bias[6]	2366	0[7]	Hedges' g -0.24 (-0.49, 0.01)		⨁◯◯◯ Very low	Critical
Carer burden and stress (higher scores indicate more severe carer burden and stress) (Cheng et al. 2020)												
12	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	Publication bias[6]	2011	0[7]	Hedges' g -0.36 (-0.57, -0.14)		⨁◯◯◯ Very low	Critical
Subjective well-being (higher scores indicate better subjective well-being) (Cheng et al. 2020)												

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
6	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	Publication bias[6]	827	0[7]	Hedges' g 0.42 (0.10, 0.75)		⊕◯◯◯ Very low	Critical
Health-related quality of life (higher scores indicate better health-related quality of life) (Lee et al. 2019)												
6	RCTs	No serious risk of bias	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[6]	462	532	Hedges' g 0.255 (0.054, 0.457)		⊕⊕⊕◯ Moderate	Critical
Measures of ability, knowledge, skills, mastery (higher scores indicate better ability, knowledge, skills, mastery) (Cheng et al. 2020)												
4	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	None	927	0[7]	Hedges' g 0.66 (0.12, 1.20)		⊕⊕◯◯ Low	Critical
Anxiety (higher scores indicate worse anxiety) (Cheng et al. 2020)												
3	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	None	339	0[7]	Hedges' g -0.68 (-1.77, 0.41)		⊕◯◯◯ Very low	Critical
Positive aspects of caregiving (higher scores indicate more positive aspects of caregiving) (Cheng et al. 2020)												
3	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	731	0[7]	Hedges' g 0.12 (-0.05, 0.28)		⊕◯◯◯ Very low	Important

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Physical health (higher scores indicate better physical health) (Cheng et al. 2020)												
4	RCTs	Serious [3]	No serious inconsistency	No serious indirectness	Serious[5]	None	734	0 [7]	Hedges' g 0.22 (-0.02, 0.46)		⨁⨁◯◯ Low	Important
Social support (higher scores indicate better social support) (Cheng et al. 2020)												
3	RCTs	Serious [3]	No serious inconsistency	No serious indirectness	No serious imprecision	None	692	0 [7]	Hedges' g 0.23 (0.08, 0.38)		⨁⨁⨁◯ Moderate	Important

CI: confidence interval; RCTs: randomized controlled trials

[1] 4 categories of quality of evidence: ⨁⨁⨁⨁ (High), ⨁⨁⨁◯ (Moderate), ⨁⨁◯◯ (Low), ⨁◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the ROB decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.

[5] Small sample size and CI around magnitude of effect

[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.

[7] Not reported.

Table 9. Remotely Delivered Interventions involving training, support or both vs usual treatment, waiting list control, attention OR control information

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are remotely delivered interventions effective for improving their outcomes?
Setting: Community
Reference List: González-Fraile E, Ballesteros J, Rueda J-R, Santos-Zorrozúa B, Solà I, McCleery J (2021). Remotely delivered information, training and support for informal caregivers of people with dementia. *Cochrane Database of Systematic Reviews,* Issue 1. Art. No.: CD006440. DOI: 10.1002/14651858.CD006440.pub3.

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depressive symptoms and mood vs usual treatment, waiting list control, attention												
8	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	322	316	SMD -0.05 (-0.22, 0.12)		⨁⨁◯◯ Low	Critical
Depressive symptoms and mood vs control information												
11	RCTs	Serious[3]	Serious[4]	No serious indirectness	No serious imprecision	None	532	568	SMD -0.25 (-0.43, -0.06)		⨁⨁◯◯ Low	Critical
Carer burden vs usual treatment, waiting list control, attention												
9	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	None	300	297	SMD -0.06 (-0.35, 0.23)		⨁◯◯◯ Very low	Critical

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Carer burden vs control information												
9	RCTs	Serious[3]	Serious[4]	No serious indirectness	Serious[5]	None	312	338	SMD -0.24 (-0.51, 0.04)		⨁◯◯◯ Very low	Critical
Health-related quality of life vs usual treatment, waiting list control, attention												
2	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	163	148	SMD 0.10 (-0.13, 0.32)		⨁⨁◯◯ Low	Critical
Health-related quality of life vs control information												
2	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	123	134	SMD -0.03 (-0.28, 0.21)		⨁⨁◯◯ Low	Critical
Caregiver knowledge and skills vs usual treatment, waiting list control, attention												
4	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	109	114	SMD 0.20 (-0.10, 0.50)		⨁⨁◯◯ Low	Critical
Caregiver knowledge and skills vs control information												
2	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	35	35	SMD 0.18 (-0.29, 0.65)		⨁⨁◯◯ Low	Critical

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Use of health and social care resources vs usual treatment, waiting list control, attention												
1	RCT	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	133	117	Rate ratio 1.05 (0.93, 1.19)		⨁⨁◯◯ Low	Important
Admission of person with dementia to institutional care vs usual treatment, waiting list control, attention												
1	RCT	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	18	16	RR 0.59 (0.11, 3.11)		⨁⨁◯◯ Low	Critical
Admission of person with dementia to institutional care vs control information												
1	RCT	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	17	15	RR 2.67 (0.12, 60.93)		⨁⨁◯◯ Low	Critical
Dropouts for any reason (acceptability) vs usual treatment, waiting list control, attention												
8	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	Serious[5]	None	341	320	RR 1.15 (0.87, 1.53)		⨁⨁◯◯ Low	Important
Dropouts for any reason (acceptability) vs control information												
12	RCTs	Serious[3]	No serious inconsistency	No serious indirectness	No serious imprecision	None	643	623	RR 1.51 (1.04, 2.20)		⨁⨁⨁◯ Moderate	Important

CI: confidence interval; RCTs: randomized controlled trials; RR – Risk Ratio; SMD: standard mean difference

[1] 4 categories of quality of evidence: ⊕⊕⊕⊕ (High), ⊕⊕⊕◯ (Moderate), ⊕⊕◯◯ (Low), ⊕◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the ROB decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.

[5] Small sample size and CI around magnitude of effect

[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.

[7] Not reported.

Table 10. Respite vs wait list control or minimal attention

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are respite interventions effective for improving their outcomes?
Setting: Community
Reference List: Walter E, Pinquart M (2020). How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. Gerontologist, 60(8):e609-e619. DOI: 10.1093/geront/gnz118

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depression (higher scores indicate more severe depressive symptoms)												
13	Non-randomized and RCT	Serious [3]	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[6]	1546	0[7]	Hedges' g -0.24 (-0.40, -0.08)		⨁◯◯◯ Very low	Critical
Carer burden (higher scores indicate more severe burden)												
15	Non-randomized and RCT	Serious [3]	No serious inconsistency	No serious indirectness	No serious imprecision	Publication bias[6]	2030	0[7]	Hedges' g -0.27 (-0.42, -0.12)		⨁◯◯◯ Very low	Critical
Subjective well-being (higher scores indicate better subjective well-being)												
6	Non-randomized and RCT	Serious [3]	No serious inconsistency	No serious indirectness	Serious[5]	None	597	0[7]	Hedges' g 0.24 (-0.06, 0.55)		⨁◯◯◯ Very low	Critical
Ability/knowledge (higher scores indicate more ability/knowledge)												

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
2	Non-randomized and RCT	Serious [3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	113	0[7]	Hedges' g -0.10 (-0.61, 0.41)		⊕◯◯◯ Very low	Critical
Anxiety (higher scores indicate worse anxiety)												
1	Non-randomized and RCT	Serious [3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	42	0[7]	Hedges' g -0.40 (-1.28, 0.48)		⊕◯◯◯ Very low	Critical
Care Recipient symptoms (e.g. neuropsychiatric symptoms and cognitive impairment; higher scores indicate worse care recipient symptoms)												
9	Non-randomized and RCT	Serious [3]	No serious inconsistency	No serious indirectness	Serious[5]	Publication bias[6]	771	0[7]	Hedges' g -0.08 (-0.26, 0.11)		⊕◯◯◯ Very low	Critical
Institutionalization												
10	Non-randomized and RCT	Serious [3]	Serious[4]	No serious indirectness	No serious imprecision	None	1467	0[7]	OR 0.80 (0.48, 1.32)		⊕◯◯◯ Very low	Critical

CI: confidence interval; OR – Odds Ratio; RCTs: randomized controlled trials;

[1] 4 categories of quality of evidence: ⊕⊕⊕⊕ (High), ⊕⊕⊕◯ (Moderate), ⊕⊕◯◯ (Low), ⊕◯◯◯ (Very low). Examples are provided in the table.
[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.
[3] Risk of bias rated according to the ROB decision tree (appendix III). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).
[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.

[5] Small sample size and CI around magnitude of effect
[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.
[7] Not reported.

Table 11. Behavioural activation vs standard care; information support; materials, information packages, psychoeducation; home visits

Author(s): Mouna Sawan, Claire O'Connor
Date: 2022
Question: For carers of people living with dementia, are behavioural activation interventions effective for improving their outcomes?
Setting: Community
Reference List: Xu, Kwan, Leung (2020). Behavioural activation for family dementia caregivers: a systematic review and meta-analysis. Geriatric Nursing, 41:544-552. DOI: 10.1016/j.gerinurse.2020.02.003

Certainty assessment							№ of patients		Effect		Certainty[1]	Importance[2]
№ of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Interventions	Control	Relative (95% CI)	Absolute (95% CI)		
Depression (higher scores indicate more severe depressive symptoms)												
9	RCTs	No serious risk of bias	Serious[4]	No serious indirectness	Serious[5]	None	401	385	SMD -0.69 (-1.12, -0.25)		⊕⊕◯◯ Low	Critical

RCT: randomized controlled trial; SMD: standard mean difference

[1] 4 categories of quality of evidence: ⊕⊕⊕⊕ (High), ⊕⊕⊕◯ (Moderate), ⊕⊕◯◯ (Low), ⊕◯◯◯ (Very low). Examples are provided in the table.

[2] 3 categories of importance: critical for decision making (Critical), important but not critical for decision making (Important), Not important for decision making – of lower importance to carers of people living with dementia.

[3] Risk of bias rated according to the ROB decision tree (appendix IV). Included studies had high risk of performance bias (>60%) and unclear risk of reporting bias (>80%).

[4] Substantial degree of heterogeneity present as suggested by an I^2 greater than 50%.

[5] Small sample size and CI around magnitude of effect

[6] Publication bias. We rated it as serious if there was evidence for publication bias in the meta-analyses, based on statistical tests.

[7] Not reported.

3.3.1. Additional evidence not mentioned in GRADE tables

Akarsu et al. 2018
This systematic review investigated the effectiveness of interventions in reducing depressive symptoms in ethnic minority carers of people with dementia. For the purpose of this review, "minority ethnic" was defined as the "common geographic origins, ancestry, family patterns, language, cultural norms and traditions, and the social history of particular groups", and groups which experienced a cultural heritage distinct to the majority population. Interventions included were psychological (e.g. CBT or family therapy) and educational multicomponent interventions. This systematic review identified 13 studies (n= 2056), six interventions were delivered to participants from a minority ethnic background, and the remaining seven were delivered to a mixed population. The majority of included studies were from the United States of America. RCTs with validated measures for depressive symptoms at baseline and in the follow-up period were included. Interventions across a variety of modalities (psychological, multicomponent, and educational) improved depression in caregivers, with a summary effect size of SMD −0.17 (95% CI, −0.29 to −0.05; P = 0.005) overall. A narrative synthesis was conducted to assess the diverse range of contexts and study characteristics and found that basic levels of cultural adaptation of interventions (for example, translating generic materials or having bilingual/bicultural staff) appeared less effective than interventions that were developed with the target ethnic minority or cultural group's preferred method of engagement in mind.

Huo et al. 2021
This study aimed to appraise the economic evidence of interventions supporting informal caregivers of people with dementia. Trial-based studies evaluating the costs and effects of interventions supporting informal caregivers of people with dementia were included. Cost data were analysed from both health care and societal perspectives. Random-effects models were used to synthesize cost and effect data, based on mean differences (MDs) or SMDs. This meta-analysis included 33 studies. Fourteen studies (42.4%) showed net savings in total cost regardless of analytical perspectives. Among 22 studies included in meta-analyses, caregiver-focused psychosocial interventions showed improvements in caregivers' psychological health (n = 4; SMD 0.240; 95% confidence interval 0.094-0.387); nevertheless, the increases in societal cost were significant (n = 5; MD 3144; 95% confidence interval 922-5366). Psychological intervention and behavioural management engaging patient-caregiver dyads showed positive effects on caregivers' subjective burden, also with increases in total cost. Subgroup analyses indicated that the inclusion of different intervention components, the caregiver characteristics, and the follow-up periods could affect the costs and effects of interventions supporting informal caregivers.

Meng et al. 2021
This meta-analysis focused on informal carers of people living with dementia. The interventions included in the review were carer education, carer skills training, social support, case management, and multicomponent interventions. There were no restrictions on the control groups, and these included routine care, telephone support, and other types of interventions. Outcomes analysed included behavioural and psychological symptoms of dementia (measured using the Neuropsychiatric Inventory [NPI] or Revized Memory and Behaviour Problems Checklist [RMBPC]), and carer reactions to BPSD. Results from the meta-analysis indicated a pooled effect size of SMD -0.12 (-0.21, -0.03; p=0.01) for BPSD. There were 12 studies that contained data on the effect of interventions on BPSD at follow-up; meta-analysis indicated significant reductions in behaviours and psychological symptoms of dementia, SMD-0.24 (-0.38, -0.09; p=0.002). For carer reactions to BPSD, the pooled effect size was SMD -0.27 (-0.43, -0.11).

4. From Evidence to Recommendations

4.1. Summary of findings

Table 12: Summary of findings table

GRADE Table	Source	Outcome	Number of Studies	Effects	Certainty of Evidence
GRADE table 1 **Psychoeducation**	Cheng et al. 2020[a] Lee et al. 2019[c]	Depressive symptoms[a-] psychoeducation A	12	Hedges' g -0.19 (-0.29, -0.08)	⊕⊕◯◯ Low
		Depressive symptoms[a-] psychoeducation B	18	Hedges' g -0.37 (-0.52, -0.23)	⊕◯◯◯ Very low
		Carer burden and stress[a-] psychoeducation A	20	Hedges' g -0.23 (-0.39, -0.07)	⊕◯◯◯ Very low
		Carer burden and stress[a-] psychoeducation B	17	Hedges' g -0.23 (-0.37, -0.08)	⊕◯◯◯ Very low
		Subjective well-being[a-] psychoeducation A	15	Hedges' g 0.20 (0.05, 0.34)	⊕⊕◯◯ Low
		Subjective well-being[a-] psychoeducation B	10	Hedges' g 0.20 (0.05, 0.35)	⊕⊕◯◯ Low
		Health related quality of life[c]	5	Hedges' g 0.163 (-0.001, 0.328)	⊕◯◯◯ Very low
		Anxiety[a -psychoeducation A	4	Hedges' g -0.15 (-0.54, 0.24)	⊕◯◯◯ Very low
		Anxiety[a - psychoeducation B	6	Hedges' g -0.20 (-0.64, 0.23)	⊕◯◯◯ Very low
		Measures of ability, knowledge, skills, mastery[a- psychoeducation A	12	Hedges' g 0.20 (0.07, 0.32)	⊕⊕◯◯ Low
		Measures of ability, knowledge, skills, mastery[a - psychoeducation B	9	Hedges' g 0.32 (0.18, 0.46)	⊕⊕◯◯ Low

GRADE Table	Source	Outcome	Number of Studies	Effects	Certainty of Evidence
		Positive aspects of caregiving [a- psychoeducation A]	2	Hedges' g 0.28 (-0.84, 1.40)	⊕◯◯◯ Very low
		Positive aspects of caregiving [a- psychoeducation B]	4	Hedges' g 0.82 (0.22, 1.41)	⊕◯◯◯ Very low
		Social Support [a- psychoeducation A]	1	Hedges' g 0.42 (-0.25, 1.08)	⊕◯◯◯ Very low
		Social Support [a- psychoeducation B]	1	Hedges' g 0.19 (-0.27, 0.65)	⊕◯◯◯ Very low
GRADE Table 2 **Counselling and psychotherapy (including CBT)**	Cheng et al. 2020[a] Lee et al. 2019[c]	Depressive symptoms[a]	9	Hedges' g -0.35 (-0.55, -0.15)	⊕◯◯◯ Very low
		Carer burden and stress[a]	6	Hedges' g -0.12 (-0.28, 0.03)	⊕◯◯◯ Very low
		Subjective well-being[a]	4	Hedges' g 0.17 (-0.06, 0.40)	⊕◯◯◯ Very low
		Health related quality of life[c]	3	Hedges' g 0.767 (0.142, 1.391)	⊕◯◯◯ Very low
		Anxiety[a]	3	Hedges' g -0.25 (-0.47, -0.03)	⊕⊕◯◯ Low
		Measures of ability, knowledge, skills, mastery[a]	3	Hedges' g 0.17 (-0.05, 0.38)	⊕◯◯◯ Very low
		Physical Health [a]	1	Hedges' g 0.14 (-0.10, 0.38)	⊕◯◯◯ Very low
GRADE Table 3 **Mindfulness-based interventions and CAM**	Cheng et al. 2020[a] Lee et al. 2019[c]	Depressive symptoms[a]	7	Hedges' g -0.58 (-0.83, -0.33)	⊕◯◯◯ Very low
		Carer burden and stress[a]	4	Hedges' g -0.20 (-0.57, 0.18)	⊕◯◯◯ Very low
		Subjective well-being[a]	6	Hedges' g 0.31 (0.03, 0.58)	⊕◯◯◯ Very low

GRADE Table	Source	Outcome	Number of Studies	Effects	Certainty of Evidence
		Health related quality of life[c]	2	Hedges' g 0.576 (0.035, 1.118)	⊕◯◯◯ Very low
		Anxiety[a]	3	Hedges' g -0.65 (-1.51, 0.21)	⊕◯◯◯ Very low
		Measures of ability, knowledge, skills, mastery[a]	3	Hedges' g 0.02 (-0.47, 0.50)	⊕◯◯◯ Very low
		Social Support[a]	1	Hedges' g 0.24 (-0.22, 0.71)	⊕◯◯◯ Very low
GRADE Table 4 **Support groups, emotional support, social support**	Cheng et al. 2020[a] Lee et al. 2019[c]	Depressive symptoms[a]	3	Hedges' g -0.11 (-0.40, 0.19)	⊕◯◯◯ Very low
		Carer burden and stress[a]	4	Hedges' g -0.20 (-0.55, 0.15)	⊕◯◯◯ Very low
		Subjective well-being[a]	4	Hedges' g 0.62 (-0.26, 1.50)	⊕◯◯◯ Very low
		Health related quality of life[c]	4	Hedges' g 0.231 (-0.104, 0.567)	⊕◯◯◯ Very low
		Anxiety[a]	1	Hedges' g -0.05 (-0.32, 0.22)	⊕◯◯◯ Very low
		Positive aspects of caregiving[a]	1	Hedges' g 0.19 (-0.20, 0.58)	⊕◯◯◯ Very low
		Social Support[a]	2	Hedges' g 0.23 (-0.27, 0.74)	⊕◯◯◯ Very low
GRADE Table 5 **Care coordination and case management**	Cheng et al. 2020[a] Lee et al. 2019[c]	Depressive symptoms[a]	6	Hedges' g -0.07 (-0.24, 0.10)	⊕◯◯◯ Very low
		Carer burden and stress[a]	12	Hedges' g -0.15 (-0.26, -0.04)	⊕⊕◯◯ Low
		Subjective well-being[a]	7	Hedges' g 0.18 (-0.03, 0.39)	⊕◯◯◯ Very low

GRADE Table	Source	Outcome	Number of Studies	Effects	Certainty of Evidence
		Health related quality of life[c]	6	Hedges' g 0.135 (-0.076, 0.346)	⊕◯◯◯ Very low
		Anxiety[a]	1	Hedges' g -0.28 (-0.73, 0.16)	⊕◯◯◯ Very low
		Measures of ability, knowledge, skills, mastery[a]	5	Hedges' g 0.08 (-0.19, 0.35)	⊕◯◯◯ Very low
		Physical health[a]	1	Hedges' g -0.05 (-0.50, 0.40)	⊕◯◯◯ Very low
		Social Support[a]	3	Hedges' g 0.04 (-0.13, 0.21)	⊕◯◯◯ Very low
GRADE Table 6 **Training of the care-recipient with caregiver involvement**	Cheng et al. 2020[a] Lee et al. 2020[b] Lee et al. 2019[c]	Depressive symptoms[a]	9	Hedges' g -0.24 (-0.46, -0.01)	⊕◯◯◯ Very low
		Depressive symptoms[b]	5	SMD -0.104 (-0.240, 0.031)	⊕⊕⊕⊕ High
		Carer burden and stress[a]	11	Hedges' g -0.12 (-0.28, 0.04)	⊕◯◯◯ Very low
		Subjective well-being[a]	8	Hedges' g 0.29 (-0.01, 0.58)	⊕◯◯◯ Very low
		Health related quality of life[c]	2	Hedges' g 0.010 (-0.208, 0.229)	⊕⊕◯◯ Low
		Anxiety[a]	3	Hedges' g -0.06 (-0.21, 0.09)	⊕⊕◯◯ Low
		Measures of ability, knowledge, skills, mastery[a]	7	Hedges' g 0.52 (0.09, 0.95)	⊕⊕◯◯ Low
GRADE Table 7 **Multicomponent Interventions**	Cheng et al. 2020[a] Lee et al. 2019[c]	Depressive symptoms[a]	12	Hedges' g -0.24 (-0.49, 0.01)	⊕◯◯◯ Very low
		Carer burden and stress[a]	12	Hedges' g -0.36 (-0.57, -0.14)	⊕◯◯◯ Very low

GRADE Table	Source	Outcome	Number of Studies	Effects	Certainty of Evidence
		Subjective well-being[a]	6	Hedges' g 0.42 (0.10, 0.75)	⊕◯◯◯ Very low
		Health related quality of life[c]	6	Hedges' g 0.255 (0.054, 0.457)	⊕⊕⊕◯ Moderate
		Anxiety[a]	3	Hedges' g -0.68 (-1.77, 0.41)	⊕◯◯◯ Very low
		Measures of ability, knowledge, skills, mastery[a]	4	Hedges' g 0.66 (0.12, 1.20)	⊕⊕◯◯ Low
		Positive aspects of caregiving[a]	3	Hedges' g 0.12 (-0.05, 0.28)	⊕◯◯◯ Very low
		Physical health[a]	4	Hedges' g 0.22 (-0.02, 0.46)	⊕⊕◯◯ Low
		Social support[a]	3	Hedges' g 0.23 (0.08, 0.38)	⊕⊕⊕◯ Moderate
GRADE Table 8 **Remotely Delivered Interventions**	Gonzales-Fraile et al. 2021 (control = usual treatment, waitlist, or attention)[d] Gonzales-Fraile et al. 2021 (control = information)[e]	Depressive symptoms[d]	8	SMD -0.05 (-0.22, 0.12)	⊕⊕◯◯ Low
		Depressive symptoms[e]	11	SMD -0.25 (-0.43, -0.06)	⊕⊕◯◯ Low
		Carer burden[d]	9	SMD -0.06 (-0.35, 0.23)	⊕◯◯◯ Very low
		Carer burden[e]	9	SMD -0.24 (-0.51, 0.04)	⊕◯◯◯ Very low
		Health related quality of life[d]	2	SMD 0.10 (-0.13, 0.32)	⊕⊕◯◯ Low
		Health related quality of life[e]	2	SMD -0.03 (-0.28, 0.21)	⊕⊕◯◯ Low
		Caregiver knowledge and skills[d]	4	SMD 0.20 (-0.10, 0.50)	⊕⊕◯◯ Low

GRADE Table	Source	Outcome	Number of Studies	Effects	Certainty of Evidence
		Caregiver knowledge and skills[e]	2	SMD 0.18 (-0.29, 0.65)	⊕⊕◯◯ Low
		Use of health and social care resources[d]	1	Rate ratio 1.05 (0.93, 1.19)	⊕⊕◯◯ Low
		Admission of person with dementia to institutional care[d]	1	RR 0.59 (0.11, 3.11)	⊕⊕◯◯ Low
		Admission of person with dementia to institutional care[e]	1	RR 2.67 (0.12, 60.93)	⊕⊕◯◯ Low
		Dropouts for any reason (acceptability)[d]	8	RR 1.15 (0.87, 1.53)	⊕⊕◯◯ Low
		Dropouts for any reason (acceptability)[e]	12	RR 1.51 (1.04, 2.20)	⊕⊕⊕◯ Moderate
GRADE Table 9 **Respite**	Walter et al. 2020	Depressive symptoms	13	Hedges' g -0.24 (-0.40, -0.08)	⊕◯◯◯ Very low
		Carer burden	15	Hedges' g -0.27 (-0.42, -0.12)	⊕◯◯◯ Very low
		Subjective well-being	6	Hedges' g 0.24 (-0.06, 0.55)	⊕◯◯◯ Very low
		Ability/knowledge	2	Hedges' g -0.10 (-0.61, 0.41)	⊕◯◯◯ Very low
		Anxiety	1	Hedges' g -0.40 (-1.28, 0.48)	⊕◯◯◯ Very low
		Care recipient symptoms	9	Hedges' g -0.08 (-0.26, 0.11)	⊕◯◯◯ Very low
		Institutionalization	10	OR 0.80 (0.48, 1.32)	⊕◯◯◯ Very low
GRADE Table 10 **BA**	Xu et al. 2020	Depressive symptoms	9	SMD -0.69 (-1.12, -0.25)	⊕⊕◯◯ Low

BA: behavioural activation; CAM: complementary and alternative medicine; CBT: cognitive behavioural therapy; OR: odd ratio; RR: risk ratio; SMD: standardized mean difference
a Cheng
b Lee (depressive symptoms)
c Lee (HRQOL)
d Gonzales-Fraile control (usual treatment, wait-list or attention)
e Gonzales-Fraile control (information)
Psychoeducation A (educational programs with *probable* psychological components to improve coping. These programs focus on increasing caregivers' knowledge of dementia and developing specific coping skills to deal with challenges in caregiving based largely on the stress-and-coping model.)
Psychoeducation B (educational programs with psychotherapeutic components such as cognitive–behavioural theories. Group psychotherapy would also be classified here if the therapeutic components are adapted for delivery in a structured psychoeducational format).

4.2. Evidence to decision table

Table 13: Evidence to decision table

Please note * indicates evidence from overarching qualitative review by Gronholm et al, 2023.

	Criteria, questions	Judgement	Research evidence	Additional considerations
Priority of the problem	Is the problem a priority? The more serious a problem is, the more likely it is that an option that addresses the problem should be a priority (e.g. diseases that are fatal or disabling are likely to be a higher priority than diseases that only cause minor distress). The more people who are affected, the more likely it is that an option that addresses the problem should be a priority.			
	• Are the consequences of the problem serious (that is, severe or important in terms of the potential benefits or savings)? • Is the problem urgent? • Is it a recognized priority (such as based on a political or policy decision)? [Not relevant when an individual patient perspective is taken]	☐ No ☐ Probably no ☐ Probably yes ☒ **Yes** ☐ Varies ☐ Don't know	The number of people living with dementia is increasing, with an estimated 10 million new cases per year (WHO, 2020). Informal carers form a vital support to people living with dementia, but the role is associated with negative impacts to a range of areas for the carers (e.g. psychological, physical, social, and financial) (Cheng 2017). The need for supportive interventions to mediate these impacts of caring for a family member with dementia is internationally recognized, reflected in the rapid growth of research in the field (Cheng et al. 2020). High levels of stress and burden associated with caring for someone with dementia predicts institutionalization of the person with dementia (HR = 1.02, P<.05; Eska et al. 2013). Compared to carers in high income countries, those in low- and middle-income countries are likely to be subject to fewer formal services and therefore experience higher levels of carer burden (Wimo et al. 2018). It is therefore vital to identify which interventions are most likely to make an impact so any services that are available may focus their approach.	None.

Criteria, questions		Judgement	Research evidence	Additional considerations
Desirable Effects	How substantial are the desirable anticipated effects? The larger the benefit, the more likely it is that an option should be recommended.			
	• Judgements for each outcome for which there is a desirable effect • How substantial (large) are the desirable anticipated effects (including health and other benefits) of the option (taking into account the severity or importance of the desirable consequences and the number of people affected)?	☐ Trivial ☒ **Small** ☐ Moderate ☐ Large ☐ Varies ☐ Don't know	**Depressive symptoms and mood** The following interventions have a small effect towards reducing depressive symptoms: psychoeducation A, psychoeducation B, counselling, and psychotherapy (including CBT), Training of the care-recipient with caregiver involvement, Remotely Delivered Interventions (vs control information), and respite. The following interventions have a medium effect towards reducing depressive symptoms: Mindfulness-based interventions and CAM and BA. **Carer burden and stress** The following interventions have a small effect towards reducing carer burden and stress: psychoeducation A, psychoeducation B, Multicomponent Interventions and respite. **Subjective well-being** The following interventions have a small effect towards improving subjective well-being: psychoeducation A, psychoeducation B, Mindfulness-based interventions, and CAM, training of the care-recipient with caregiver involvement, and multicomponent Interventions.	None.

Criteria, questions	Judgement	Research evidence	Additional considerations
		Health-related quality of life Multicomponent Interventions have a small effect towards improving health related quality of life. The following interventions have a medium effect towards improving health related quality of life: counselling and psychotherapy (including CBT), Mindfulness-based interventions and CAM. **Anxiety** Counselling and psychotherapy (including CBT) has a small effect towards reducing anxiety. **Measures of ability, knowledge, skills, mastery** The following interventions have a small effect towards improving measures of ability, knowledge, skills, mastery: psychoeducation A, psychoeducation B. The following interventions have a medium effect towards improving measures of ability, knowledge, skills, mastery: Training of the care-recipient with caregiver involvement, & Multicomponent Interventions. **Positive aspects of caregiving** psychoeducation B has a large effect towards improving positive aspects of caregiving. **Social support** Multicomponent Interventions have a small effect towards improving social support.	

Criteria, questions		Judgement	Research evidence	Additional considerations
Undesirable Effects	How substantial are the undesirable anticipated effects? The greater the harm, the less likely it is that an option should be recommended.			
	• Judgments for each outcome for which there is an undesirable effect • How substantial (large) are the undesirable anticipated effects (including harms to health and other harms) of the option (taking into account the severity or importance of the adverse effects and the number of people affected)?	☐ Large ☐ Moderate ☐ Small ☒ **Trivial** ☐ Varies ☐ Don't know	None of the studies reported adverse outcomes or any harms identified as a result of any of the interventions. It is anticipated that an adverse impacts from these non-pharmacological interventions would be minimal, and the potential benefits would outweigh any added burden that participation may entail. Gonzalez-Fraile et al. (2021) commented on the uncertainty around access to carer support interventions in low and middle-income countries.	None.
Certainty of evidence	What is the overall certainty of the evidence of effects? The less certain the evidence is for critical outcomes (those that are driving a recommendation), the less likely that an option should be recommended (or the more important it is likely to be to conduct a pilot study or impact evaluation, if it is recommended).			
	• What is the overall certainty of this evidence of effects, across all of the outcomes that are critical to making a decision? • See GRADE guidance regarding detailed judgements about the quality of evidence or certainty in estimates of effects	☐ Very low ☒ **Low** ☐ Moderate ☐ High ☐ No included studies	**Psychoeducation** The evidence for the use of psychoeducation to support carers of people with dementia is of low to very low certainty. Overall, the certainty is very low. **Counselling and psychotherapy (including CBT)** The evidence for the use of counselling and psychotherapy (including CBT) to support carers of people with dementia is of low to very low certainty. Overall, the certainty is very low. **Mindfulness-based interventions and CAM**	None.

Criteria, questions	Judgement	Research evidence	Additional considerations
		The evidence for the use of mindfulness-based interventions and CAM to support carers of people with dementia is of very low certainty. **Support groups, emotional support, social support** The evidence for the use of support groups, emotional support, social support to support carers of people with dementia is of very low certainty. **Care coordination and case management** The evidence for the use of care coordination and case management to support carers of people with dementia is of low to very low certainty. Overall, the certainty is very low. **Training of the care-recipient with caregiver involvement** The evidence for the use of training of the care-recipient with caregiver involvement to support carers of people with dementia is of high to very low certainty. Overall, the certainty is low. **Multicomponent Interventions** The evidence for the use of multicomponent Interventions to support carers of people with dementia is of moderate to very low certainty. Overall, the certainty is very low. **Remotely delivered interventions** The evidence for the use of multicomponent Interventions to support carers of people with dementia is of moderate to very low certainty. Overall, the evidence certainty is low.	

Criteria, questions		Judgement	Research evidence	Additional considerations
			Behavioural activation The evidence for the use of BA to support carers of people with dementia is of low certainty. **Respite** The evidence for the use of respite to support carers of people with dementia is of very low certainty.	
Values	Is there important uncertainty about or variability in how much people value the main outcomes? The more likely it is that differences in values would lead to different decisions, the less likely it is that there will be a consensus that an option is a priority (or the more important it is likely to be to obtain evidence of the values of those affected by the option). Values in this context refer to the relative importance of the outcomes of interest (how much people value each of those outcomes). These values are sometimes called 'utility values'.			
	• Is there important uncertainty about how much people value each of the main outcomes? • Is there important variability in how much people value each of the main outcomes?	☐ Important uncertainty or variability ☐ Possibly important uncertainty or variability ☒ **Probably no important uncertainty or variability** ☐ No important uncertainty or variability	The importance of outcomes for carers of people living with dementia were rated as either critical for decision making or important but not critical for decision making. The majority were rated as critical.	

Criteria, questions		Judgement	Research evidence	Additional considerations
Balance of effects	Does the balance between desirable and undesirable effects favour the intervention or the comparison? The larger the desirable effects in relation to the undesirable effects, taking into account the values of those affected (i.e. the relative value they attach to the desirable and undesirable outcomes) the more likely it is that an option should be recommended.			
	• Judgements regarding each of the four preceding criteria • To what extent do the following considerations influence the balance between the desirable and undesirable effects: - How much less people value outcomes that are in the future compared to outcomes that occur now (their discount rates)? - People's attitudes towards undesirable effects (how risk averse they are)? - People's attitudes towards desirable effects (how risk seeking they are)?	☐ favours the comparison ☐ Probably favours the comparison ☐ Does not favour either the intervention or the comparison ☒ **Probably favours the intervention** ☐ favours the intervention ☐ Varies ☐ Don't know	While the evidence for non-pharmacological interventions to support carers of people living with dementia is variable, none of the studies reported adverse outcomes or any harms identified as a result of any of the interventions. Therefore, it is probable that the potential benefits would outweigh any added burden that participation may entail.	
Resources required	How large are the resource requirements (costs)? The greater the cost, the less likely it is that an option should be a priority. Conversely, the greater the savings, the more likely it is that an option should be a priority.			
	• How large is the difference in each item of resource use for which fewer resources are required? • How large is the difference in each item of resource use for which more resources are required? • How large an investment of resources would the option require or save?	☐ Large costs ☐ Moderate costs ☐ Negligible costs and savings ☐ Moderate savings ☐ Large savings	We did not see any cost study in the selected reviews. But, in 3.3.1. (studies not included in the GRADE table) we report one systematic review on this subject by Huo et al. (2021). Fourteen studies (42.4%) showed net savings in total cost regardless of analytical perspectives. Among 22 studies included in	

Criteria, questions		Judgement	Research evidence	Additional considerations
		☒ **Varies** ☐ Don't know	meta-analyses, caregiver-focused psychosocial interventions showed improvements in caregivers' psychological health; nevertheless, the increases in societal cost were significant (n = 5; MD 3144; 95% confidence interval 922-5366). Psychological intervention and behavioural management engaging patient-caregiver dyads showed positive effects on caregivers' subjective burden, also with increases in total cost. Subgroup analyses indicated that the inclusion of different intervention components, the caregiver characteristics, and the follow-up periods could affect the costs and effects of interventions supporting informal caregivers.	
Certainty of evidence of required resources	What is the certainty of the evidence of resource requirements (costs)?			
	• Have all-important items of resource use that may differ between the options being considered been identified? • How certain is the evidence of differences in resource use between the options being considered (see GRADE guidance regarding detailed judgements about the quality of evidence or certainty in estimates)? • How certain is the cost of the items of resource use that differ between the options being considered? • Is there important variability in the cost of the items of resource use that differ between the options being considered?	☐ Very low ☐ Low ☐ Moderate ☐ High ☒ **No included studies**	No reviews examining resources were identified.	
Cost effectiveness	Does the cost-effectiveness of the intervention favour the intervention or the comparison? The greater the cost per unit of benefit, the less likely it is that an option should be a priority.			
	• Judgements regarding each of the six preceding criteria • Is the cost effectiveness ratio sensitive to one-way sensitivity analyses?	☐ favours the comparison ☐ Probably favours the comparison	No reviews examining cost effectiveness were identified	

Criteria, questions		Judgement	Research evidence	Additional considerations
	• Is the cost effectiveness ratio sensitive to multivariable sensitivity analysis? • Is the economic evaluation on which the cost effectiveness estimate is based reliable? • Is the economic evaluation on which the cost effectiveness estimate is based applicable to the setting(s) of interest?	☐ Does not favour either the intervention or the comparison ☐ Probably favours the intervention ☐ favours the intervention ☐ Varies **☒ No included studies**		
Health equity, equality and non-discrimination	What would be the impact on health equity, equality, and non-discrimination? (WHO INTEGRATE) Health equity and equality reflect a concerted and sustained effort to improve health for individuals across all populations, and to reduce avoidable systematic differences in how health and its determinants are distributed. Equality is linked to the legal principle of non-discrimination, which is designed to ensure that individuals or population groups do not experience discrimination on the basis of their sex, age, ethnicity, culture or language, sexual orientation or gender identity, disability status, education, socioeconomic status, place of residence or any other characteristics. All recommendations should be in accordance with universal human rights standards and principles. The greater the likelihood that the intervention increases health equity and/or equality and that it reduces discrimination against any particular group, the greater the likelihood of a general recommendation in favour of this intervention.			
	• How are the condition and its determinants distributed across different population groups? Is the intervention likely to reduce or increase existing health inequalities and/or health inequities? Does the intervention prioritize and/or aid those furthest behind? • How are the benefits and harms of the intervention distributed across the population? Who carries the burden (e.g. all), who benefits (e.g. a very small sub-group)? • How affordable is the intervention for individuals, workplaces or communities? • How accessible - in terms of physical as well as informational access - is the intervention across different population groups?	☐ Reduced ☐Probably reduced ☐Probably no impact **☒ Probably increased** ☐ Increased ☐ Varies ☐ Don't know	There was no direct evidence to evaluate impact on health equity, equality and non-discrimination. The qualitative review (Gronholm et al., 2023) noted considerations for ensuring mental, neurological and substance use interventions are equitable, equally available and non-discriminatory: • Accessibility, physical/practical considerations • time & travel constraints. • Accessibility, informational barriers • Affordability - treatment costs • These factors may be exacerbated for certain groups:	

Criteria, questions		Judgement	Research evidence	Additional considerations
	• Is there any suitable alternative to addressing the condition, does the intervention represent the only available option? Is this option proportionate to the need, and will it be subject to periodic review?		• People with low education/literacy (e.g., written instructions, psychoeducation materials) • Women - travel restrictions, stronger stigma/shame, caregiving • responsibilities • • Low resource settings - affordability/cost considerations exacerbated.	
Feasibility	Is the intervention feasible to implement? The less feasible (capable of being accomplished or brought about) an option is, the less likely it is that it should be recommended (i.e. the more barriers there are that would be difficult to overcome).			
	• Can the option be accomplished or brought about? • Is the intervention or option sustainable? • Are there important barriers that are likely to limit the feasibility of implementing the intervention (option) or require consideration when implementing it?	☐ No ☐ Probably no ☒ **Probably yes** ☐ Yes ☐ Varies ☐ Don't know	There was no direct evidence to evaluate feasibility to implement the interventions. The qualitative review (Gronholm et al., 2023) also considered feasibility, and how this can be enhanced in the following areas: • Acceptability of interventions for stakeholders - requires increased engagement with specialist staff, increased visibility of the task-sharing workforce within health facilities, perception of usefulness by providers and service users (e.g., via positive feedback), context-specific interventions, standardised implementation steps for simpler decision-making and delivery • Health worker workload, competency - requires training, refreshers, supervision; networking with others in same role • Availability of a task-sharing workforce	

Criteria, questions		Judgement	Research evidence	Additional considerations
			• Participant education and literacy requires verbal explanations/tasks • Logistical issues - such as e.g., mobile populations, affordability of travel to receive care, lack of private space • Limited resources/mental health budget Sustainability considerations identified were: • Training and supervision • Integrating into routine clinical practice Common barriers to accessing carer services/interventions (Bayly et al., 2020): • Low awareness of available services • Cost of service, transportation challenges • Need for respite and difficulty getting the person with dementia to services • Values and beliefs (e.g. reluctance to reach out for help, belief that family should provide care) • Stigma around dementia and the use of support services, service not meeting a need/ incompatible • As well as time restrictions (WHO iSupport evaluation)	

Criteria, questions		Judgement	Research evidence	Additional considerations
Human rights and sociocultural acceptability	Is the intervention aligned with human rights principles and socioculturally acceptable? (WHO INTEGRATE) This criterion encompasses two distinct constructs: The first refers to an intervention's compliance with universal human rights standards and other considerations laid out in international human rights law beyond the right to health (as the right to health provides the basis of other criteria and sub-criteria in this framework). The second, sociocultural acceptability, is highly time-specific and context-specific and reflects the extent to which those implementing or benefiting from an intervention as well as other relevant stakeholder groups consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention. The greater the sociocultural acceptability of an intervention to all or most relevant stakeholders, the greater the likelihood of a general recommendation in favour of this intervention.			
	• Is the intervention in accordance with universal human rights standards and principles? • Is the intervention socioculturally acceptable to patients/beneficiaries as well as to those implementing it? To which extent do patients/beneficiaries value different non-health outcomes? • Is the intervention socioculturally acceptable to the public and other relevant stakeholder groups? Is the intervention sensitive to sex, age, ethnicity, culture or language, sexual orientation or gender identity, disability status, education, socioeconomic status, place of residence or any other relevant characteristics? • How does the intervention affect an individual's, population groups or organization's autonomy, i.e. their ability to make a competent, informed and voluntary decision? • How intrusive is the intervention, ranging from low intrusiveness (e.g. providing information) to intermediate intrusiveness (e.g. guiding choices) to high intrusiveness (e.g. restricting or eliminating choices)? Where applicable, are high intrusiveness and/or impacts on the privacy and dignity of concerned stakeholders justified?	☐ No ☐ Probably no ☒ **Probably yes** ☐ Yes ☐ Varies ☐ Don't know	There was no direct evidence to evaluate alignment with human rights principle and socio-cultural acceptability. The qualitative review (Gronholm et al., 2023) noted several considerations which would impact the right to health and access to healthcare. (e.g., stigma and discrimination and lack of confidentiality could affect the helpseeking among service users). • The importance of socio-cultural acceptability of mental, neurological and substance use interventions was clearly expressed. Pre-intervention considerations that consider cultural and social aspects improve the acceptability of implemented interventions. • When interventions were perceived as appropriate for the culture and target group, the content and medium of the intervention received more positive feedback from service users and caregivers Also, considerations of age, sex and language have been highlighted as important to acceptability and accessibility.	

Criteria, questions		Judgement	Research evidence	Additional considerations
			Mitigating steps to improve sociocultural acceptability include: • To train health workers in non-judgemental care • Integrate preventative mental health awareness messages to reduce the stigma • Train acceptable counsellors for the local settings and target groups • Facilitate the use of indigenous/ local phrases and terms to increase acceptability.	

BA: behavioural activation; CAM: complementary and alternative medicine; CBT: cognitive behavioural therapy; HR: hazard ratio; MD: mean difference; WHO: world health organization

4.3. Summary of judgements

Table 14: Summary of judgements

Priority of the problem	- Don't know	- Varies		- No	- Probably No	- Probably Yes	✓ **Yes**
Desirable effects	- Don't know	- Varies		- Trivial	✓ **Small**	- Moderate	- Large
Undesirable effects	- Don't know	- Varies		- Large	- Moderate	- Small	✓ **Trivial**
Certainty of the evidence	- No included studies			Very low	✓ **Low**	- Moderate	- High
Values				- Important uncertainty or variability	- Possibly important uncertainty or variability	✓ **Probably no important uncertainty or variability**	- No important uncertainty or variability
Balance of effects	- Don't know	- Varies	- Favours comparison	- Probably favours comparison	- Does not favour either	✓ **Probably favours intervention**	- Favours intervention
Resources required	- Don't know	✓ **Varies**	- Large costs	- Moderate costs	- Negligible costs or savings	- Moderate savings	- Large savings
Certainty of the evidence on required resources	✓ **No included studies**			- Very low	- Low	- Moderate	- High
Cost–effectiveness	✓ **No included studies**	- Varies	- Favours comparison	- Probably favours comparison	- Does not favour either	- Probably favours intervention	- Favours intervention
Equity, equality and non-discrimination	- Don't know	- Varies	- Reduced	Probably reduced	- Probably no impact	✓ **Probably increased**	- Increased
Feasibility	- Don't know	- Varies		- No	- Probably No	✓ **Probably Yes**	- Yes
Human rights and sociocultural acceptability	- Don't know	- Varies		- No	- Probably No	✓ **Probably Yes**	- Yes

✓ Indicates category selected, - Indicates category not selected

5. References

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Appendix I: mhGAP process note

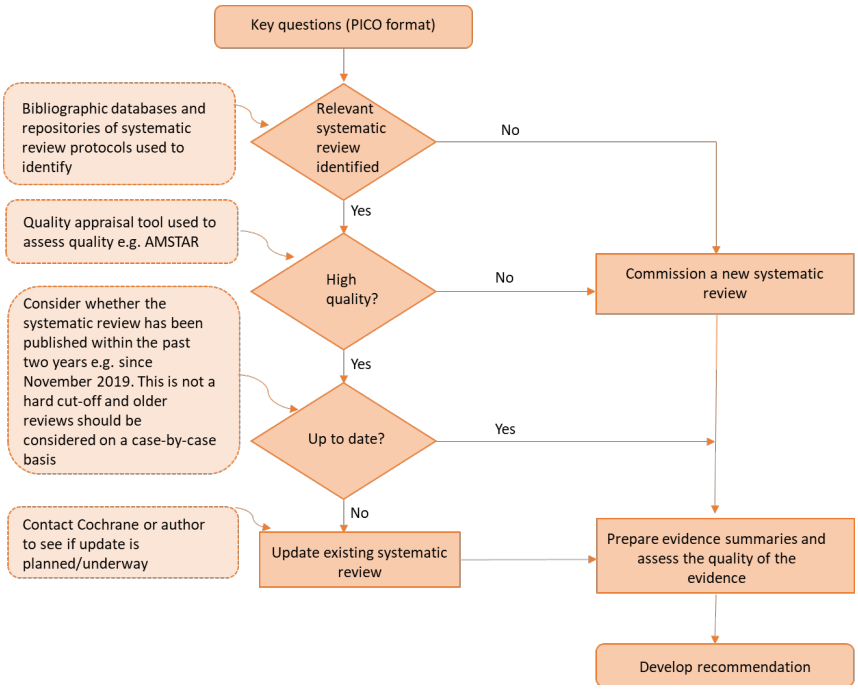
mhGAP Guideline Update: Notes on process for identifying level of evidence review required v1_0 (09/11/2021)

This document is intended to provide guidance to focal points on the level of evidence review required as part of the evidence retrieval process for the mhGAP guideline update process.
As a general rule, the update process should be informed by existing high-quality systematic reviews. The process for evidence retrieval and synthesis is fully outlined in chapter 8 of the WHO handbook for guideline development https://apps.who.int/iris/handle/10665/145714.

Three main categories of evidence review are proposed in this document:
i) Existing relevant, up to date, high-quality systematic review(s) provide the evidence required. **An existing systematic review is sufficient to prepare the evidence summaries**. It may be possible to include more than one systematic review for the same PICO, as different reviews may match different outcomes of a PICO. However, if more than one systematic review is available for the same PICO outcome, one review should be selected, based on quality, relevance, search comprehensiveness and date of last update. The selection process should be transparently reported, with justification of choices.
ii) Existing high quality systematic reviews are either out of date or do not fully address the PICO, though it is considered that the review can be updated to meet these requirements. **An update of an existing systematic review is required before the evidence summaries can be prepared**. The update process may require addition of new studies published after the review, or inclusion of outcomes not covered by the existing reviews.
iii) Existing systematic reviews are either not of sufficiently high quality or cannot be updated to fully address the PICO. **A new systematic review is required before the evidence summaries can be prepared.**

Figure 1 below details the process to identify which level of evidence review is required to support the evidence retrieval process for a PICO.

Figure 1: Is a new systematic review needed?



Subsequent steps include the following:

i) **Identify and evaluate existing systematic reviews**: Identify one or more systematic review(s) to address each PICO question. Existing systematic reviews will inform the guideline development process, whether a new systematic review or an update of an existing review is required, and the evidence review team will detail existing systematic reviews in each case. The method for identifying existing systematic reviews should be fully detailed in the evidence summary and include the following sources:

a. Search of bibliographic databases, such as PubMed/MEDLINE, EMBASE, PsycInfo, Cochrane Central Register of Controlled Trials (CENTRAL), CINAHIL, Scopus, African Index Medicus, Index Medicus for the Eastern Mediterranean Region, Index Medicus for the South-East Asian Region, Latin American and Caribbean Health Sciences Literature, and Western Pacific Region Index Medicus.

b. Search of repositories of systematic reviews protocols, including PROSPERO, Open Science Framework (OSF), and Cochrane.

ii) **Assess if systematic review is up to date:** It is preferred that identified systematic reviews have been published within the past two years e.g. since November 2019. This is not a hard cut-off and older reviews should be considered on a case-by-case basis, particularly those covering the time period since the last update of the mhGAP guideline in 2015. It is acknowledged that COVID has led to a pausing of many mental health research activities over the past two years, and this may also impact the availability of systematic reviews within the preferred two-year period. For any reviews that fall outside the two-year period, the guideline methodologist will advise on suitability.

iii) **Appraise quality of systematic review:** Use the AMSTAR quality appraisal tool to assess the quality of the identified systematic review(s) https://amstar.ca/Amstar_Checklist.php . This includes consideration of the extent to which the PICO is fully addressed by the systematic review(s) identified.

By following the process outlined in figure 1, and steps 1-3 above, the focal point and evidence review team will have sufficient evidence to assess which of the three main categories of evidence review apply to each PICO under consideration:

a) Existing systematic reviews are sufficient to prepare the evidence summaries.

b) An update of an existing systematic review is required before the evidence summaries can be prepared.

c) A new systematic review is required before the evidence summaries can be prepared.

Appendix II: Search terms used to identify systematic reviews

Overview of results

Database	Result	Date
MEDLINE	267	02/02/2022
CINAHL	292	02/02/2022
Embase	390	02/02/2022
SCOPUS	329	02/02/2022
Cochrane Library	595	02/02/2022
PsyINFO	121	02/02/2022
Global Index Medicus	19	02/02/2022
EPISTEMONIKOS	0	02/02/2022
Total (with Duplicate)	**2013**	

Search strategy (PICO table/ concept mapping table)

Concept 1	Concept 2	Concept 3	Concept 4
Dementia	Caregiver	Daycare	Systematic Review
Alzheimer	Carer Spouse Relatives Family member Support person Family Friend Siblings Unpaid carer Daughter Son Wife Husband Offspring Informal Carer	Day Centre Respite Psychoeducation cognitive behavioral therapy Counseling Case Management Peer Support Training Self-help Psychosocial Psychological Multi-component Environmental	Meta-Analysis

Database results

1.1 DATABASE: MEDLINE via OVIDSP

Database: Ovid MEDLINE(R) ALL <1946 to February 01, 2022>

Search Strategy:

---

1 exp Dementia/ (186456)
2 Dementia*.mp. (145106)
3 Alzheimer*.mp. (181167)
4 1 or 2 or 3 (290034)
5 Caregivers/ (44145)
6 Caregiver*.mp. (92434)
7 (Carer* or informal carer*).mp. (17002)
8 Spouses/ (11090)
9 spouse*.mp. (32821)
10 relati*.mp. (4270180)

11 Family member*.mp. (101164)
12 Support person*.mp. (1726)
13 Family/ (81358)
14 Family*.mp. (1089244)
15 Friends/ (6097)
16 Friend*.mp. (108212)
17 Siblings/ (12499)
18 Sibling*.mp. (58550)
19 Unpaid Carer*.mp. (100)
20 exp Nuclear Family/ or Nuclear famil*.mp. (156620)
21 (Daughter* or son* or wife or husband).mp. (226826)
22 Offspring*.mp. (81826)
23 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (5543271)
24 Day Care, Medical/ (5199)
25 Day care*.mp. (15139)
26 Day cent*.mp. (749)
27 Respite Care/ (1073)
28 Respite*.mp. (2473)
29 psychoeducation*.mp. (6030)
30 Cognitive Behavioral Therapy/ (28391)
31 (cognitive-behavio* therap* or cognitive behavio* therap*).mp. (36326)
32 Counseling/ (38165)
33 Counselling.mp. (30560)
34 Case Management/ (10411)
35 Case management*.mp. (17920)
36 Peer support*.mp. (5907)
37 Training.mp. (513974)
38 Self-Help Groups/ (9435)
39 Self help*.mp. (20408)
40 psychosocial*.mp. (112318)
41 psychological*.mp. (627907)
42 multi-component*.mp. (7052)
43 environmental*.mp. (794376)
44 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 (2066342)
45 "systematic review"/ (184031)
46 Systematic review*.mp. (262024)
47 "systematic review".pt. (184031)
48 Systematic Reviews as Topic/ (7384)
49 Primarily systematic review*.mp. (2)
50 meta-analysis/ (152103)
51 meta?analysis*.mp. (1827)
52 45 or 46 or 47 or 48 or 49 or 50 or 51 (331859)
53 4 and 23 and 44 and 52 (665)
54 limit 53 to yr="2019 -Current" (267)

1.2 DATABASE: CINAHL via EBSCO Host

#	Query	Results
S54	S4 AND S27 AND S46 AND S52 Limiters - Published Date: 20190101-20221231	292
S53	S4 AND S27 AND S46 AND S52	790
S52	S47 OR S48 OR S49 OR S50 OR S51	187,490
S51	meta?analysis*	4,469
S50	(MH "Meta Analysis")	60,058
S49	""Primarily systematic review*""	47
S48	systematic review*	170,083
S47	(MH "Systematic Review")	106,207
S46	S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45	1,128,439
S45	"environmental*"	93,813
S44	"multi-component*"	1,460
S43	psychological*	288,724
S42	"psychosocial*"	581,408
S41	Self help*	8,129
S40	"Self-Help Groups"	6,004
S39	"Training"	253,819
S38	Peer support*	8,154
S37	(MH "Case Management") OR "Case management*"	21,454
S36	Counsel*	90,056
S35	(MH "Counseling+")	41,663
S34	"cognitive-behavio* therap*" OR "cognitive behavio* therap*"	10,932
S33	"psychoeducation*"	5,569
S32	Respite*	2,538
S31	(MH "Respite Care")	1,439
S30	"Day centre*"	335
S29	(MH "Day Care") OR "Day care*"	7,499
S28	"Medical daycare"	3

S27	S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26	1,382,529
S26	"Offspring*"	14,406
S25	"Spous*" OR (MH "Spouses")	18,835
S24	"Wife"	9,823
S23	(MH "Sons")	575
S22	"daughter*"	6,663
S21	Nuclear famil*	1,531
S20	(MH "Nuclear Family+")	119,959
S19	unpaid care worker*	11
S18	"Unpaid Carer*"	101
S17	"Sibling*"	14,359
S16	"friend*"	43,989
S15	(MH "Family+") OR "Family*"	461,249
S14	"Support person*"	1,186
S13	"Family member*"	31,850
S12	relati*	1,020,306
S11	spouse*	18,319
S10	(MH "Spouses")	11,868
S9	"informal carer*"	1,023
S8	"informal carer*"	0
S7	"Carer*"	37,228
S6	Caregiver*	77,641
S5	(MH "Caregivers")	39,356
S4	S1 OR S2 OR S3	104,582
S3	Alzheimer*	48,562
S2	Dementia*	72,397
S1	(MH "Dementia+")	80,001

1.3 DATABASE: Embase via OVID SP

Database: Embase Classic <1947 to 1973>, Embase <1974 to 2022 February 01>
Search Strategy:
---
1 exp dementia/ (402379)
2 Dementia*.mp. (228397)
3 Alzheimer*.mp. (272276)
4 1 or 2 or 3 (470260)
5 caregiver/ (96055)
6 Caregiver*.mp. (136446)
7 (Carer* or Informal Carer*).mp. (25528)
8 spouse/ (18494)
9 spouse*.mp. (31574)
10 relative/ (15884)
11 relati*.mp. (4859215)
12 Family member*.mp. (135269)
13 Support person*.mp. (2236)
14 family/ (97124)
15 Famil*.mp. (1691555)
16 friend/ (23882)
17 Friend*.mp. (134873)
18 sibling/ (49312)
19 Sibling*.mp. (87088)
20 Unpaid Carer*.mp. (124)
21 nuclear family/ (3063)
22 Nuclear Famil*.mp. (5467)
23 daughter/ (6083)
24 Daughter*.mp. (38026)
25 son/ (5046)
26 Son*.mp. (357659)
27 wife/ (1680)
28 Wife.mp. (9318)
29 husband/ (2435)
30 Husband.mp. (10626)
31 Offspring*.mp. (100820)
32 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 (6764611)
33 day care/ (12657)
34 Day care*.mp. (17166)
35 Day cent*.mp. (1143)
36 respite care/ (1211)
37 Respite*.mp. (3237)
38 psychoeducation/ (9547)
39 psychoeducation*.mp. (13932)
40 cognitive behavioral therapy/ (17879)
41 (cognitive-behavio* therap* or cognitive behavio* therap*).mp. (36758)
42 counseling/ (74597)
43 Counsel*.mp. (248909)
44 case management/ (12646)

45 Case management*.mp. (20669)
46 Peer support*.mp. (8181)
47 training/ (97446)
48 Training.mp. (737779)
49 peer group/ (26801)
50 Peer group*.mp. (28741)
51 self help/ (14259)
52 (Self help or self-help*).mp. (20579)
53 psychosocial*.mp. (168749)
54 psychological*.mp. (838156)
55 multi-component*.mp. (9714)
56 environmental*.mp. (951237)
57 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 (2844906)
58 "systematic review"/ (330453)
59 Systematic review*.mp. (429629)
60 "systematic review (topic)"/ (28139)
61 Primarily systematic review*.mp. (2)
62 meta analysis/ (236289)
63 meta?analysis*.mp. (9698)
64 58 or 59 or 60 or 61 or 62 or 63 (524042)
65 4 and 32 and 57 and 64 (1106)
66 limit 65 to yr="2019 -Current" (390)

1.4 DATABASE: Scopus via Elsivier

329 document results
(TITLE-ABS-KEY (dementia* OR alzheimer*) AND TITLE-ABS-KEY (caregiver* OR carer* OR spouse* OR relati* OR "Family member*" OR "Support person*" OR famil* OR friend* OR sibiling* OR "unpaid carer*" OR daughter* OR son* OR wife OR husband* OR offspring* OR "informal carer*") AND TITLE-ABS-KEY ("Day care*" OR "Day cent*" OR respite* OR psychoeducation* OR "cognitive-behavio* therap*" OR "cognitive behavio* therap*" OR counsel* OR "Case management*" OR "Peer support*" OR training OR "Self help*" OR psychosocial* OR psychological* OR "multi-component*" OR environmental*) AND TITLE-ABS-KEY ("Systematic review*" OR "Primarily systematic review*" OR "meta?analysis*")) AND (LIMIT-TO (PUBYEAR , 2022) OR LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019))

1.5 DATABASE: Cochrane Library via OVID-SP

Database: EBM Reviews - NHS Economic Evaluation Database <1st Quarter 2016>, EBM Reviews - Health Technology Assessment <4th Quarter 2016>, EBM Reviews - Cochrane Methodology Register <3rd Quarter 2012>, EBM Reviews - Cochrane Database of Systematic Reviews <2005 to January 26, 2022>, EBM Reviews - ACP Journal Club <1991 to January 2022>, EBM Reviews - Database of Abstracts of Reviews of Effects <1st Quarter 2016>, EBM Reviews - Cochrane Clinical Answers <January 2022>, EBM Reviews - Cochrane Central Register of Controlled Trials <December 2021>
Search Strategy:
---
1 Dementia*.mp. (16813)
2 Alzheimer*.mp. (14008)
3 1 or 2 (24702)
4 Caregiver*.mp. (18162)

5 (Carer* or informal carer*).mp. (6153)
6 spouse*.mp. (2592)
7 relati*.mp. (257047)
8 Family member*.mp. (5700)
9 Support person*.mp. (457)
10 Family*.mp. (44971)
11 Friend*.mp. (6652)
12 Sibling*.mp. (2520)
13 Unpaid Carer*.mp. (23)
14 Nuclear famil*.mp. (144)
15 (Daughter* or son* or wife or husband).mp. (20461)
16 Offspring*.mp. (2057)
17 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 (318012)
18 Day care*.mp. (2234)
19 Day cent*.mp. (200)
20 Respite*.mp. (283)
21 psychoeducation*.mp. (4727)
22 (cognitive-behavio* therap* or cognitive behavio* therap*).mp. (19897)
23 Counsel*.mp. (29633)
24 Case management*.mp. (3236)
25 Peer support*.mp. (1690)
26 Training.mp. (112574)
27 Self-Help Groups/ (753)
28 Self help*.mp. (4939)
29 psychosocial*.mp. (20103)
30 psychological*.mp. (60394)
31 multi-component*.mp. (1961)
32 environmental*.mp. (12827)
33 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 (224436)
34 Systematic review*.mp. (69210)
35 Primarily systematic review*.mp. (2)
36 meta-analysis/ (23)
37 meta?analysis*.mp. (1357)
38 34 or 35 or 36 or 37 (69955)
39 3 and 17 and 33 and 38 (595)

1.6 DATABASE: PsycInfo via OVID-SP

Database: APA PsycInfo <1806 to January Week 4 2022>
Search Strategy:
---
1 exp Dementia/ (84392)
2 Dementia*.mp. (81942)
3 Alzheimer*.mp. (71165)
4 1 or 2 or 3 (118370)
5 exp Caregivers/ (32410)
6 Caregiver*.mp. (67371)
7 (Carer* or Informal Carer*).mp. (11627)
8 exp Spouses/ (16448)
9 spouse*.mp. (32514)
10 relati*.mp. (1481151)

11 exp Family Members/ (183185)
12 Family member*.mp. (48759)
13 Support person*.mp. (1481)
14 exp Family/ (322205)
15 Family*.mp. (382527)
16 Friend*.mp. (76203)
17 exp Siblings/ (15582)
18 Sibling*.mp. (25069)
19 Unpaid Carer*.mp. (55)
20 exp Nuclear Family/ (482)
21 Nuclear Famil*.mp. (3065)
22 exp Daughters/ or Daughter*.mp. (14068)
23 exp Sons/ or Son*.mp. (42773)
24 Wife.mp. or exp Wives/ (10494)
25 exp Husbands/ or Husband*.mp. (15108)
26 Offspring*.mp. or exp Offspring/ (34287)
27 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 (1837827)
28 exp Adult Day Care/ (392)
29 Day care*.mp. (7995)
30 Day cent*.mp. (636)
31 exp Respite Care/ (475)
32 Respite*.mp. (1926)
33 exp Psychoeducation/ (5018)
34 psychoeducation*.mp. (11943)
35 (cognitive-behavio* therap* or cognitive behavio* therap*).mp. (33566)
36 exp Counseling/ (80453)
37 Counsel*.mp. (134742)
38 exp Case Management/ (3820)
39 Case management*.mp. (7834)
40 Peer support*.mp. (5417)
41 exp Training/ (83071)
42 Training.mp. (308175)
43 Self-Help Group*.mp. (4643)
44 Self-help*.mp. (13701)
45 psychosocial*.mp. (124341)
46 psychological*.mp. (552204)
47 multi-component*.mp. (1493)
48 environmental*.mp. (119313)
49 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 (1160074)
50 exp "Systematic Review"/ (681)
51 Systematic review*.mp. (38795)
52 exp Meta Analysis/ (5137)
53 meta?analysis*.mp. (460)
54 meta-analysis*.mp. (37026)
55 50 or 51 or 52 or 53 or 54 (65284)
56 4 and 27 and 49 and 55 (385)
57 limit 56 to yr="2019 -Current" (121)

1.7 EPISTEMONIKOS (https://www.epistemonikos.org)
0 results

(title:(dementia* OR alzheimer*) OR abstract:(dementia* OR alzheimer*)) AND (title:(caregiver* OR carer* OR spouse* OR relati* OR "Family member*" OR "Support person*" OR famil* OR friend* OR sibiling* OR "unpaid carer*" OR daughter* OR son* OR wife OR husband* OR offspring* OR "informal carer*") OR abstract:(caregiver* OR carer* OR spouse* OR relati* OR "Family member*" OR "Support person*" OR famil* OR friend* OR sibiling* OR "unpaid carer*" OR daughter* OR son* OR wife OR husband* OR offspring* OR "informal carer*")) AND (title:(Day care*" OR "Day centre" OR respite* OR psychoeducation* OR "cognitive-behavio* therap*" OR "cognitive behavio* therap*" OR counsel* OR "Case management*" OR "Peer support*" OR training OR "Self help*" OR psychosocial* OR psychological* OR "multi-component*" OR environmental*) OR abstract:(Day care*" OR "Day cent*" OR respite* OR psychoeducation* OR "cognitive-behavio* therap*" OR "cognitive behavio* therap*" OR counsel* OR "Case management*" OR "Peer support*" OR training OR "Self help*" OR psychosocial* OR psychological* OR "multi-component*" OR environmental*))

1.8 Global Health Medicus

31 results
(tw:(dementia)) AND (tw:(Therapy or Therapies)) AND (tw:(Systematic*)) AND 2019-2022

Appendix III: Choosing a database: comparative table of six

Database	**Scope**	**Coverage**	**Bibliographic / Full-Text**	**Includes Subject Headings (Thesaurus)**	**Citation limit when exporting to Endnote**
MEDLINE via OvidSP	Biomedical	1946 – present 18,000,000 references indexing over 5,200 journals	Bibliographic (full text access for subscribed e-Journals)	Medical Subject Headings (MeSH)	999
Embase via OvidSP	Pharmacy and biomedical	1947 – present 20,000,000 references indexing 7,000 journals	Bibliographic	Emtree	999
PubMed (free version of MEDLINE)	Biomedical plus some general science, chemistry and molecular biology.	1946 (some earlier) – present 21,000,000 references indexing over 23,000 journals. Contains in-process citations for articles before they are indexed for MEDLINE	Bibliographic (full text access for subscribed e-Journals)	MeSH for material from MEDLINE	Not recommended for systematic review searches
Web of Science	Multi-disciplinary including Science, social Science, and arts and humanities	1900 – present (science related material) 46,000,000 references indexing over 12,000 journals and 148,000 proceedings	Bibliographic (full text access for subscribed e-Journals)	WOS doesn't have a thesaurus or list of subject terms. Key concepts need to be identified and linked together.	500
Scopus	Multi-disciplinary including chemistry, science, and arts and humanities	1996- present Over 21,500 titles (Over 21,500 peer-reviewed journals (including 4,200 full open access journals); Over 60 million records • Patents: • More than 27 million patent records from five patent offices	Bibliographic (full text access for subscribed e-Journals	Scopus doesn't have a thesaurus or list of subject terms. Key concepts need to be identified and linked together	2000
Cinahl via Ebsco	Nursing, biomedicine, health sciences, alternative/ complementary medicine, consumer health and 17 allied health disciplines	1982- present Provides indexing for over 2,928 journals from the fields of nursing and allied health	Bibliographic (full text access for subscribed e-Journals	Enter the search terms in the Find field, check the Suggest Subject Terms box and click Search. Note: You can also browse CINAHL or MeSH Headings by clicking the link in the top toolbar.	Add 50 at a time to the Folder, then export from Folder

4. Differences in search syntax: MEDLINE vs CINAHL

Syntax feature	MEDLINE	Symbol	CINAHL	Symbol	Scopus	Symbol
Subject	MeSH (Explode or Focus) – searches only the subject headings field. Tick box 'Map to Subject Headings'	MeSH	Searches only the subject headings field. Automatically explodes the term. To use, tick box 'Suggested Subject Terms' and type in search term		No subject	
Keyword	Textword search: Title and Abstract only Multipurpose search: Title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier No need to untick Map to subject headings, just add **.mp** or **.tw** to the search term and click **Search**	.tw .mp	Untick "suggested subject terms" mapping option and type in the search term. Searches: Title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier Alternatively, use Field codes IN FRONT of keywords, eg. **TX keyword**	TX keyword (in CINAHL) = keyword .mp (in MEDLINE)	Nested search <u>Example:</u> (dogs OR cats) AND (house OR apartment)	
Adjacency	Finds words or phrases within selected number of words from one another in either order, e.g. health adj3 promotion find health promotion and promotion of health	adj*(number)*	Finds words or phrases within selected number of words from one another in either order, e.g. health N3 promotion finds health promotion and promotion of health	N*(number)*	Finds words or phrases within selected number of words from one another in either order, e.g. health W/3 promotion finds promotion of health	W/number
Optional Wildcard	Replaces 0-1 character e.g. p?ediatric finds pediatric or paediatric	?	Replaces 0-1 character, e.g. p#ediatric finds pediatric or paediatric	#	n/a	
Mandated Wildcard	Replaces 1 character e.g. wom#n finds woman or women	#	Replaces 1 character, e.g. wom?n finds woman or women	?	Replaces 1 character, e.g. wom?n finds woman or women; not essential (Scopus does it automatically anyway)	?
Truncation	Finds any extension of the root term – unlimited characters, e.g. imag* will find image, images, imaging or imagination	*OR $	Finds any extension of the root term – unlimited characters; e.g imag* will find image, images, imaging or imagination	*	Finds any extension of the root term – unlimited characters; e.g imag* will find image, images, imaging or imagination	*
Phrases	Phrases ONLY need be enclosed in quotation marks if they contain words such as AND, OR, NOT, OF etc.(stop words)		Use quotation marks to search for phrases	"-"	Use quotation marks to search for phrases	"-" OR {}

Appendix IV: Decision Tree used to evaluate ROB GRADE item

Figure: Developed tree for the assessment of the risk of bias item in GRADE (DEP4. In adults with moderate-severe depressive disorder, what is the effectiveness and safety of antidepressant medication (ADM) in comparison with psychological treatment?)

- No data available for risk of bias → serious

- When vast majority (>60%) of trials are low risk → not serious
- When low risk is between 50-60%:
  - High risk <25% → not serious
  - High risk >25% → serious

- When vast majority (>60%) is high risk → very serious
- When high risk is between 50-60%:
  - Low risk <25% → very serious
  - Low risk >25% → serious

- When vast majority is unclear risk (>60%) → serious
- When unclear risk is between 50-60%:
  - High risk <25% → not serious
  - High risk >25% → serious

- If unclear/high/low risk are all < 50%:
  - High risk <25% → not serious
  - High risk >25% → serious