

## PROSPERO International prospective register of systematic reviews

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### Psychoeducational interventions for informal caregivers of people with dementia: a systematic review

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#### Review question(s)

Our research questions are:

1. What psychoeducational interventions have been found to be effective for carers of people with dementia and how effective are they?
2. What psychoeducational interventions have been found to be cost effective for carers of people with dementia and how cost-effective are they?
3. What patient and carer outcomes have been identified/measured in studies of psychoeducational interventions for carers of people with dementia?
4. What research is there, if any, on the effect of carers of people with dementia using validated instruments to measure/monitor the progression of dementia?
5. What are the perceptions and views of carers and patients on potential psychoeducational and monitoring interventions?
6. What are health professionals' perceptions and views of a formal monitoring role for carers of people with dementia?

#### Searches

Electronic database searches will be performed in Database of Abstracts of Reviews of Effects (DARE), The National Health Service Economic Evaluation Database (NHS EED), The Cochrane Library, National Institute for Health and Care Excellence (NICE) library, MEDLINE, Excerpta Medica dataBASE (EMBASE), SCIE (Social Care Institute for Excellence), PsycINFO, AMED, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Applied Social Sciences Index and Abstracts (ASSIA), CSA Social Services Abstracts, and EBSCOhost.

This search will be supplemented by searching Google, Google Scholar, Social Care Institute for Excellence, King's Fund, and the Health Foundation websites for grey literature. All databases will be searched from inception to present. Reference lists from the articles identified will also be scanned to ensure identification and inclusion of all relevant studies. Any missing, unpublished or in-progress studies will be obtained by contacting experts in the field. Only peer-reviewed studies published in English will be considered.

#### Types of study to be included

Eligible study designs will include: randomised controlled trials, randomised clinical controlled trials, controlled before and after trials, quasi-experimental studies, cohort studies, and observational studies. For Research Questions 5 and 6 ("What are the perceptions and views of carers and patients on potential psychoeducational and monitoring interventions?" and "What are health professionals' perceptions and views of a formal monitoring role for carers of people with dementia?" respectively), it is anticipated that very few, if any, previous interventions will be available for inclusion due to the novelty of this topic and, thus, this review will include all existing qualitative (interviews,

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focus groups) and quantitative studies (cross-sectional and longitudinal studies).

### **Condition or domain being studied**

Our main aim is to systematically review the literature on psychoeducational interventions that individually or in combination have been shown to be effective/cost-effective for improving outcomes for carers and patients with dementia; and to systematically review the literature on carers of people with dementia undertaking a formal monitoring role.

### **Participants/ population**

Studies will be eligible for inclusion if the participants involved are principal informal (unpaid) carers of people with dementia and patients with early dementia. Additionally, for Research Question 6 (“What are health professionals’ perceptions and views of a formal monitoring role for carers of people with dementia?”), studies will be eligible for inclusion if they include health professionals and they report their perceptions and views of a formal monitoring role for carers of people with early dementia.

### **Intervention(s), exposure(s)**

The studies considered will be educational interventions, psychoeducational interventions, studies involving behavioural management skills training and/or skill-building training.

### **Comparator(s)/ control**

Possible comparison groups may include control groups (e.g. ‘treatment as usual’ or ‘standard care’), before and after intervention groups, or groups undergoing different types of interventions.

### **Context**

Community-dwelling patients with dementia and their informal, unpaid carers.

Studies will be excluded if they do not meet the quality criteria proposed by the National Institute for Health and Clinical Excellence public health guidelines (NICE).

### **Outcome(s)**

#### **Primary outcomes**

Studies will be eligible for inclusion if they report outcomes, such as effectiveness of interventions, cost effectiveness of interventions, changes in morale, motivation, self-efficacy, institutionalization, burden, wellbeing, quality of life, depression, stress, and/or coping abilities. For Research Question 5 (“What are the perceptions and views of carers and patients on potential psychoeducational and monitoring interventions?”), studies will be considered for inclusion if they focus on the perceptions and views of carers of people with dementia and patients with early dementia on psychoeducational and monitoring interventions. For Research Question 6 (“What are health professionals’ perceptions and views of a formal monitoring role for carers of people with dementia?”), studies will be eligible for inclusion if they include health professionals and they report their perceptions and views of a formal monitoring role for carers of people with early dementia.

Studies will be considered for inclusion if they utilise effectiveness measures, such as Quality of Life measures, effect sizes, and/or Quality Adjusted Life Years. Possible outcome measures will include (but not be confined to) the Mini Mental State Examination, Zarit Carer Burden Interview, Beck Depression Inventory, Hospital Anxiety and Depression Scale. In addition, outcome measures that require the caregiver’s active participation will also be included. Possible measures will include (but not be confined to) the Mini Mental State Examination (MMSE), the Spontaneous Behaviour Interview rating scale (SBI), the Informant Questionnaire on Cognitive Decline (IQCODE), the Alzheimer Disease caregiver questionnaire and the Dementia Severity Rating Scale (DSRS).

#### **Secondary outcomes**

None

### **Data extraction, (selection and coding)**

All studies will be reviewed and screened by two independent reviewers (DL & JM). Initially titles and abstracts will be screened for relevance to the review, whereas final eligibility will be assessed through full-text screening against

the inclusion criteria using a pre-designed study selection form. Any possible discrepancies and/or disagreements will be resolved by discussion and consensus, and in consultation with a third reviewer if needed.

The data needed for the systematic review will be extracted using a data extraction form designed specifically for this review and following the data extraction form suggested by the National Institute for Health and Clinical Excellence public health (intervention and programme) guidance. This will include information on participant characteristics (e.g. gender, age, socioeconomic status, ethnicity, marital status, type of relationship to care recipient, mean age, gender), study characteristics (e.g. country of conduct, year, study design, type of intervention, comparison groups), outcomes (e.g. changes in morale, motivation, self-efficacy, institutionalization, burden, wellbeing, quality of life, depression) and outcome measures (e.g. QALY, MMSE, BDI, HADS, IQCODE, DSRs). Two review authors (DL & JM) will extract the data independently and any inconsistencies will be resolved through discussion. If any of the data presented in the studies is unclear or missing, the authors of primary studies will be contacted for clarification.

### **Risk of bias (quality) assessment**

The methodological quality of the studies included in the review will be assessed based on the quality criteria for critical appraisal proposed by the National Institute for Health and Clinical Excellence public health (intervention and programme) guidance. These guidelines were chosen mainly because they provide guidance on how to synthesise evidence from different kinds of research, and in particular, how to combine quantitative and qualitative data, which is an important aspect of this systematic review. Accordingly, quality criteria for appraisal of the studies will include follow-ups, attrition rates, blinding of researchers (e.g. when scoring test etc.), randomisation methods/procedures, selective reporting of outcomes, and publication bias.

Two reviewers (DL & JM) will independently assess each study for their methodological quality. Any disagreements will be resolved by discussion and consensus and in consultation with a third reviewer if needed. Furthermore, we will attempt to minimize the risk for publication bias by conducting a broad search, including grey literature and unpublished studies.

### **Strategy for data synthesis**

A narrative review of all eligible studies, along with an evidence table summarising the findings, will be provided and organised under six main themes according to this review's six objectives. It is anticipated that the identified studies will be rather heterogeneous and therefore no quantitative synthesis will be used.

### **Analysis of subgroups or subsets**

None planned

### **Dissemination plans**

Results of this systematic review will primarily inform the creation of a new educational intervention for carers of patients with dementia but will also be disseminated via high impact journals and relevant peer reviewed publications and will be presented at national primary care (e.g. Society of Academic Primary Care) and Educational research conferences. Additionally, findings will be disseminated through local conferences and educational events to carers of people with dementia, practitioners and commissioners.

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**Details of any existing review of the same topic by the same authors**

Not applicable.

**Anticipated or actual start date**

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**Anticipated completion date**

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**Conflicts of interest**

None known

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England

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Subject indexing assigned by CRD

**Subject index terms**

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**Stage of review**

Ongoing

**Date of registration in PROSPERO**

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**Date of publication of this revision**

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<b>Stage of review at time of this submission</b>	<b>Started</b>	<b>Completed</b>
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	Yes	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

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