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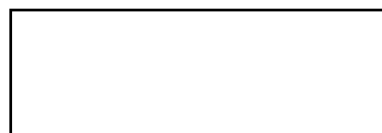
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PROSPERO International prospective register of systematic reviews

Family carers' preferences for support when caring for a family member at the end of life at home: protocol for an integrative literature review

Maria Larsson, Siew Hwa Lee, Bodil Wilde-Larsson, Cecilia Olsson, Kaisa Bjuresäter, Reidun Hov, Ellen Karine Grov, Catriona Kennedy

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Review question(s)

The aim of this integrative review is to explore the evidence base of family carers' preferences for support during end of life care in their own home.

1. What preferences for support do family carers have during end of life care in their own home and do they get what they prefer?
2. What helps family carers to cope during end of life care in their own home and do they get what they need?
3. How does organisation of end of life care at home affect family carers' experiences?
4. Is there evidence of cost effectiveness of interventions for family carers' support at home?
5. What are the key areas to guide planning intervention studies?

Searches

Published studies will be searched for in the following databases:

The Cochrane Library (Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials (CENTRAL) Cochrane Methodology Register), MEDLINE, EMBASE, CINAHL, PsycINFO, AMED, ASSIA, TRIP, ISI Web of Science and Scopus.

Key terms:

The following key term searches will be conducted:

('Palliative care' OR 'terminal care' OR 'supportive care' OR 'end of life care' OR 'domiciliary care' OR 'anticipatory care' OR 'advance care planning' OR death OR dying) AND (Home) AND (family, carers OR caregivers) AND (preferences OR experiences OR satisfaction OR support).

Other sources

- Unpublished work (grey literature) which are not published in accessible formats or indexed in the academic databases above. Examples include conference proceedings.
- Hand searching articles from the reference list of included articles will be performed to ensure completeness.
- On-going work and research in progress by searching relevant internet databases:

- www.who.int/ictrp/en/

- www.clinicaltrials.gov
- www.controlledtrials.com
- www.anzctr.org.au
- Carers UK <http://www.carersuk.org/>
- Eurocarers <http://www.eurocarers.org>
- <http://www.nrpv.se/>
- <http://palliativtutvecklingscentrum.se/>
- www.palliativ.se

Limits to include:

- Studies performed in Europe, North America or Australasia;
- Publications between 2000 and 2016;
- Literature written in English language only.

Literature obtained from the search will be stored in EndNote Web and referenced according to Harvard referencing style.

Types of study to be included

Empirical studies (quantitative, qualitative and mixed-methods studies) will be included.

We will exclude systematic reviews, editorials, commentaries or letters, discussion papers, opinion papers and non-empirical studies.

Condition or domain being studied

End of life care at home is becoming more frequent as a result of improvements in life expectancy and an increase in significant disease burden requiring specialised palliative care. Approximately 60% of patients in palliative care wish to die at home as it is regarded as a more comfortable and dignified experience (Hudson et al. 2010). This could not be achieved without informal family carers, who consequently often have to handle difficult situations and patients' complex needs by themselves. In addition, family carers themselves have a range of physical, emotional and social needs when caring for a family member at the end of life (Bee et al. 2007). In Europe there are estimated to be 100 million family carers, a number which continues to rise (Eurocarers 2008). Around 90% of the last year of life is spent at home away from hospital or hospice. Across a number of jurisdictions, particularly in Europe, policy directives emphasise the contributions and expectations of informal family carers. Caring for a family member who is dying is physically and emotionally draining. Furthermore the experience of family carers of the last year of life to the death of their family member is thought to influence the grieving process into bereavement and beyond (Harding et al. 2015; Kennedy 2008). Family carers often report unmet needs for support from the health care services (Ventura et al. 2014). With the increased demand for developing home-based palliative care there is a need to examine the evidence of family carers' preferences for support as this could inform health care personnel, decision making authorities and researchers about the design and evaluation of high quality home based end of life care.

Participants/ population

Inclusion population:

- Family carers 18 years of age and above.
- Family carers as defined by the NICE definition.

- Family carers providing end of life care in the home.

Exclusion population:

- Formal and paid carers who are not defined as 'family carers' according to the NICE definition.
- Family carers providing end of life care to children below 18 years, persons with dementia, severe cognitive impairment or learning disabilities.
- Other settings e.g. acute hospital, care home or hospice.

Intervention(s), exposure(s)

Inclusion:

- Physical, educational, emotional and social care interventions to support palliative, supportive or end of life care by family carers at own home.

Exclusion:

- Research studies not performed in Europe, North America or Australasia.

Comparator(s)/ control

Not applicable.

Context

Studies will focus on the home setting.

Outcome(s)

Primary outcomes

Family carers' preferences for physical, educational, emotional and social support during end of life care at home.

Cost-effectiveness of interventions for family carers at the end of life at home.

Secondary outcomes

None.

Data extraction, (selection and coding)

One reviewer (SHL) will search the databases. The review team will then be divided into pairs and screen titles, abstracts and full texts to ensure inclusion of relevant studies. Full texts will be assessed against the inclusion criteria. If disagreements occur, consensus will be used or a third reviewer will arbitrate. Selected full texts will be allocated to pairs of reviewers for extraction and coding of data. The selection process will be carried out in accordance with the PRISMA guidelines (Moher et al. 2009).

Methodological rigour will be assured through the involvement of at least two reviewers at each stage of the review process. This will include screening titles, abstracts and full texts to ensure the inclusion of relevant papers, data extraction and coding.

We will explore the use of EPPI-Reviewer 4, as supported by the Cochrane Collaboration, which helps manage all stages of the systematic review process from bibliographic management, screening, coding through to synthesis. EPPI-Reviewer 4 supports different analytic functions for synthesis including meta-analysis, empirical synthesis and qualitative thematic synthesis.

Risk of bias (quality) assessment

Qualitative studies will be evaluated using criteria outlined by Noyes and Popay (2007). Quantitative studies will be assessed in line with the Cochrane Collaboration and Scottish Intercollegiate Guidelines Network (SIGN) (2012) criteria including the assessment of risk of bias. The overall quality of included studies will be evaluated using the

SIGN taxonomy of evidence.

Strategy for data synthesis

An integrative analysis consisting of meta-analysis (where possible), empirical synthesis and qualitative thematic synthesis will be undertaken to group findings addressing the same phenomenon rather than reporting by method (Sandelowski et al. 2006; Whittmore and Knaf 2005).

Analysis of subgroups or subsets

None planned.

Dissemination plans

The findings will inform health care systems in United Kingdom, Sweden and Norway and beyond.

The findings will be published in a peer reviewed journal appropriate in the field.

The findings will be presented at international conferences (e.g. European Association for Palliative Care, European Oncology Nursing Society and national counterparts).

Contact details for further information

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None known

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English

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Subject indexing assigned by CRD

Subject index terms

Caregivers; Family; Health Care Costs; Humans; Palliative Care; Terminal Care

Stage of review

Ongoing

Date of registration in PROSPERO

18 April 2016

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19 April 2016

Stage of review at time of this submission

Preliminary searches

Started

Yes

Completed

Yes

Piloting of the study selection process

Yes

Yes

Formal screening of search results against eligibility criteria

No

No

Data extraction

No

No

Risk of bias (quality) assessment

No

No

Data analysis

No

No

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