

Marie Curie Research Grants Scheme

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Supporting people bereaved through advanced illness: A systematic review of the evidence and development of a core outcome set for bereavement research in palliative care.

Duration of project: 21 months

Start date: 01/02/2016

Budget: £83,489.95

Abstract

Background

Organisations which provide palliative and end of life care have an important role to play in providing bereavement support to the loved ones of patients. However, despite the existence of diverse providers, there is a deficit of systematic reviews and evidence based guidance on the key components of bereavement service provision and outcomes in palliative care. Heterogeneity in outcomes and measures used in bereavement research further limits the comparability and utility of studies for informing practice. The development of a core outcome set (COS) is a means of improving the evidence base for clinical interventions. The COS represents the 'minimum that should be measured and reported in all clinical trials of a specific condition' [www.comet-initiative.org], thus making it easier for the results of studies to be compared, contrasted and combined.

Aims

1. To systematically review the evidence on supportive interventions for people bereaved through advanced, progressive illness, answering these questions;
 - What interventions are used to support which groups of people?
 - What outcomes have been used to measure effectiveness?
 - What evidence is there for the effectiveness of these interventions for different groups of people?
 - What are the critical features of these interventions?
 - What evidence is there on the economic outcomes of these interventions?
2. To develop a set of core outcomes that is specific to bereavement support following bereavement through advanced or chronic illness, and is applicable to both research and clinical practice.

Methods

There are two distinct phases in the project which correspond with the above objectives;

1. Systematic Review:

Key databases (Medline, PsycINFO, Embase, Cinahl) will be searched using indexed terms and key words. Supplementary searches will also be conducted. This mixed methods review will include studies conducted in the UK or comparable countries reporting evaluations of bereavement interventions or services, delivered to adults bereaved through advanced, progressive illness. Study quality will be assessed using appropriate GATE checklists. Evidence will be synthesised following a thematic approach and where possible results of quantitative studies will be combined and compared using meta-analytic techniques. Full details of the search strategy and review protocol are available via Prospero, <http://www.crd.york.ac.uk/PROSPERO> (ref: CRD42016043530).

2. Core Outcome Set (COS)

The COS will be developed through a series of distinct methodologies. First, outcomes utilised in the studies identified by the systematic review will be mapped into different domains. Second, an expert consensus day will be convened with up to 30 stakeholders to identify any further potential outcomes. Finally, the list of core outcomes will be refined through an online Delphi survey with items rated over two rounds to reach consensus on which items should be included in the COS. The expert panel and survey participants will include policy makers, academics, health and social care professionals, and bereaved caregivers.

Outcomes

The review will help to identify the types of bereavement support available, the impact and effectiveness of such support, the critical features of interventions and services, and how such support might be improved. Gaps in the evidence base will be identified with recommendations for further research. The development of a core outcome set (COS) for bereavement research in palliative care has been registered with COMET and will facilitate consistency and comparison between future studies, thus ultimately improving the evidence base on bereavement support. The COS will also be developed so that it promotes consistency in the outcomes used for the commissioning and delivery of bereavement services in palliative care in the UK.