

Marie Curie Research Grants Scheme

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The development of evidence-based good practice guidelines and resources to support children and young people pre-bereavement

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Research abstract

Background

Every year in the UK, 41,000 children and young people are bereaved of a parent. The death of a primary caregiver can have long-term effects upon those bereaved before the age of 18, with negative impacts upon their emotional and physical health. There is limited evidence to suggest that improved communication and support prior to the death of a primary carer can ameliorate some of these long-term effects. The majority of data generated in this area have been retrospective studies exploring the experience of adults bereaved as children, research involving the surviving parent, or studies based upon professional opinion. Rarely are the voices of children and young people sought. There is no evidence-based guidance available to professionals working with children and young people pre-bereavement. There is anecdotal evidence that professionals find working with this population particularly challenging, believing that they lack the skills or experience to support children and young people facing the death of a primary carer. There is a gap in the evidence base and a need for primary research in this area, as well as good practice guidelines to support clinicians in the field.

Aim

This study aims to determine the needs and preferences of children and young people for pre-bereavement support, and to use this primary data to generate evidence-based feasible and acceptable guidance and resources, which will be widely disseminated to health and social care professionals.

Methods

This mixed methods study is underpinned by a social constructionist epistemology and will involve 3 sequential phases:

Phase 1: A systematic review of the literature employing an integrative review methodology, to answer the question: "What is the evidence of pre-bereavement experiences and support needs among children and young people?"

Phase 2: Primary qualitative cross-sectional research. The findings of the Phase 1 will be used to inform a semi structured topic guide for children and young people (aged 6-17), who have a parent or primary caregiver with a life-threatening illness and with recently bereaved children and young people (aged 6-17) who are bereaved of a parent or primary caregiver less than one year previously. Recruitment will be via the Palliative Care Teams at King's College Hospital and Guy's and St. Thomas' Hospital, and via St. Christopher's Hospice in South London. This will be supplemented with recruitment via social media and by approaching the collaborating online network of bereavement organisations (*The Good Grief Trust* will also recruit to the study). A purposive sample of 20 children and young people with diverse demographic characteristics will be recruited. One-to-one semi-structured interviews will be conducted with participants. Art-based techniques will be employed with younger participants to supplement the interviews and encourage engagement with the researcher. Adolescent participants will be offered the option of being interviewed by phone or online via Skype. Due to the sensitivity of the subject matter, a robust distress protocol will be implemented. The interviews will be audio-recorded and transcribed verbatim. After import into Nvivo software, data will be analysed using thematic analysis.

Phase 3: The development of evidence-based guidelines and resources. Themes generated from the data will provide the basis for good practice guidelines to be used by professionals from health, education and social care who work with children and young people facing the death of a primary carer. The data will also provide the basis of free resources to be used by professionals with children and young people pre-bereavement. The guidelines and resources will be developed using established guideline development frameworks, by our multi-professional academic, clinical and advocacy stakeholders, and with end-users.

Proposed findings

The study will produce findings that are reflective of the voices of children and young people facing a bereavement. These findings will provide the basis of clinical guidelines which will be disseminated widely through professional networks within health, social care and education. The findings will provide a valuable source of knowledge that will also be presented at academic conferences and submitted to peer-reviewed journals. Social media will also be employed as a source of dissemination. The findings will be synthesised into freely downloadable visual media that are accessible to a lay audience. The findings will therefore provide evidence-based best practice with children and young people pre-bereavement.