Design and test an eLearning resource to equip professionals supporting adults at end of life with caregiving responsibilities for children, <18 years

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Introduction

Families are often unsure how best to prepare children (<18) for the end-of-life experience of a significant adult caregiver with a poor cancer prognosis.[1] Children less prepared for the death of a significant caregiver are at greater risk of adverse outcomes.[2]

Health and social care professionals (professionals) are ideally placed to support families, as they prepare children for this end-of-life experience.[3]

Professionals report a lack of knowledge and confidence when supporting adults at end-of-life regarding children, highlighting a need for training.[3]

Aim of study

To plan, develop and test an evidence-based and theory-driven eLearning resource to equip professionals to communicate with, and support families at end-of-life regarding the children using the 'Person-based Approach.[4]

@cancer_care_uu

FCCC-EoLEd
Family-centred Cancer Care - End of Life Education
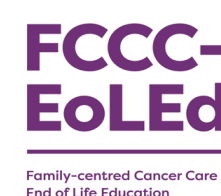
Methods

Planning the eLearning resource

A systematic review was conducted to determine the content, mode of delivery, assessment, and outcomes of educational interventions within this aspect of family-centred cancer care.

A logic model and guiding principles were developed highlighting the distinctive features of the resource required to achieve the project objectives.

Development of the eLearning resource

eLearning resource content

Included evidence-based information on the impact of parental cancer from our team's empirical studies [ulster.ac.uk/fccc], co-produced educational videos, and a communication framework.

Content was reviewed and refined through collective consultation with expert groups members (n=5) and a bereaved mum as a PPI representative. Key changes predominately related to terminology, with the PPI voice being integral. The resource prototype was developed in collaboration with a team of learning technologists across a five-month period.

Testing the eLearning resource

Research design

One-to-one 'think-aloud' interviews were conducted remotely. An iterative approach to data analysis was utilised to enact changes.

Participants

Thirteen experienced professionals took part in 'think-aloud' interviews, across three iterative cycles. Four expert group members and three PPI individuals also provided one-to-one feedback.

Data analysis

Positive and negative comments were extracted from all user-feedback. The 'Must Have, Should Have, Could Have, Would Like' (MoSCoW) 5 criteria, supported team decisions about adoption of modifications.

Key findings

The systematic review identified a paucity of research in this area (n = 2).

The systematic and iterative 'Person-based Approach' optimised the acceptability of a novel resource to promote relevance, appropriateness, and applicability.

Planned and targeted PPI input resulted in modifications to promote inclusivity and reach of the resource. This was highly beneficial in promoting rigour, relevance and quality of the eLearning resource.

The eLearning resource is LIVE.

To access, scan the QR code or the webpage to register a free account.

fccceoled.com

References
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