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Development and evaluation of an intervention to support family caregivers of people with cancer to provide home-based care at the end of life: A feasibility study

K. Luker ^{a,*}, M. Cooke ^a, L. Dunn ^a, M. Lloyd-Williams ^b, M. Pilling ^a, C. Todd ^a^a School of Nursing, Midwifery and Social Work, University of Manchester, Oxford Road, Manchester M13 9PL, UK^b Academic Palliative and Supportive Care Studies Group, Institute of Psychology, Health and Society, Department of Health Services Research, University of Liverpool, Liverpool L69 3GL, UK

A B S T R A C T

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Purpose: To design and evaluate an intervention to address carers' needs for practical information and support skills when caring for a person with cancer at end of life.

Method: **Phase 1** 29 carers were interviewed about need for practical information, support skills and their preferences for information delivery. The preferred format was a booklet. **Phase 2** evaluated the booklet. 31 carers and 14 district nurses participated. Validated questionnaires: on perceptions of caregiving and carer health before and after the booklet was used and interviews with both carers and nurses were undertaken. 24 carers completed both interviews. Quantitative data were coded using scale manuals and analysed using SPSSv20 and interview data was analysed thematically.

Results: Carers were aged 31–82 and cared for people aged 50–92; 8 carers were male and 23 female; 20 cared for a partner, 8 for a parent and 1 for a sibling (2 undisclosed).

Carers were positive about the booklet, however many carers would have liked the booklet earlier. Carers reported feeling more positive about caregiving, and more reassured and competent in their role. District nurses found the booklet useful and reported receiving fewer phone calls from study carers than others in similar situations.

Conclusions: The booklet intervention was a source of reassurance to carers and it has the potential to be incorporated into everyday practice. The challenge is in when and how to distribute the booklet and more work is required on the timing of delivery in order to maximise the usefulness of booklet to carers.

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Introduction

Studies of family members' experiences of caring towards the end of life attest to the physical and psycho-social impact of caregiving (Stajduhar et al., 2010; Funk et al., 2010; Hudson and Payne, 2011; Grande et al., 2009; Coristine et al., 2003; BurrIDGE et al., 2009). Poor control of physical symptoms from advanced cancer may result in psychological distress for both patients and carers (Hodgson et al., 1997). Caregiving demands at this phase may be particularly difficult when family members lack skills and resources.

Carers' needs for information and support have been widely studied (Harding and Higginson, 2003; Campbell et al., 2009; Adams et al., 2009; Harding et al., 2012). Carers of family members with advanced cancer have reported a range of practical information needs that include management of pain, fatigue, depression, weight and appetite loss (Wong et al., 2002; Bee et al., 2008). Some family members who look after patients with cancer may be ambivalent to caregiving because of their perceived incapacity to care (Coristine et al., 2003). Carers have mentioned difficulties in knowing what symptoms to monitor, how to interpret symptoms accurately and when to contact a professional. Studies of end-of-life care report on the poor quality of information provided by health professionals and suggest that family carers need more practical information and help, yet there is little evidence that home based palliative care services focus sufficiently on assisting carers to acquire or use practical nursing skills (Bee et al., 2008; Caress et al., 2009).

* Corresponding author. Tel.: +44 (0)161 306 0262; fax: +44 (0)161 306 7867.
E-mail addresses: Karen.A.Luker@manchester.ac.uk (K. Luker), Mary.Cooke@manchester.ac.uk (M. Cooke), Laurie.Dunn@manchester.ac.uk (L. Dunn), MLW@liverpool.ac.uk (M. Lloyd-Williams), Mark.Pilling@manchester.ac.uk (M. Pilling), Chris.Todd@manchester.ac.uk (C. Todd).

Most patients, when asked, report that they wish to die at home (Higginson and Sen-Gupta, 2000; Department of Health 2008). Carers who cannot cope with the demands of managing care and patient symptoms (even with home support), may abandon home care and request an emergency transfer of their loved one to hospital (Wiese et al., 2008). Nonetheless many people are cared for at home with the support of district nurses (DN's), other specialist nurses and general practitioners (GPs). Such contact with health care staff may provide opportunities for family carers to learn caregiving and palliative care skills, which could help prevent hospital admissions.

There is little research to date on the benefits of physically focussed home care interventions for carers of family members receiving palliative care (Hudson et al., 2005). Research is needed that focuses on well defined and evaluated interventions, which offer practical information and identify skills that enable carers to provide optimal care, while maintaining their own health and wellbeing.

Aims of study

The aims were twofold: a) to develop an intervention to address carers' needs for practical information, support and skills b) to conduct a pragmatic evaluation of the intervention as to its: i) acceptability to family carers, ii) acceptability to health care professionals and feasibility to adopt into their everyday practice, and iii) outcomes for family carers (e.g. caregiver burden and satisfaction, competence, preparedness to care).

The study was guided by the MRC framework for the design and evaluation of complex interventions (Medical Research Council, 2008). This guidance emphasises an iterative and cyclical approach and clearly conceptualizing the problem under study within its context. This aids the development and understanding of the intervention, and optimises the evaluation process. The study was reviewed and accepted by the UK National Research Ethics Service REC reference 11/H1014/3 in February 2011.

Study design sampling and methods

Study design

The study was structured into two phases. Phase 1 focussed on the development of the intervention and phase 2 evaluated the intervention from the frame of reference of carers and District Nurses (DNs).

Developing the intervention phase 1

The aim was to develop an intervention based on available evidence (Bee et al., 2008; Caress et al., 2009), and to extend the evidence through individual and group interviews with current and recently bereaved carers. As outlined in the MRC guidance, we were attuned to contextual factors and recognised that a well-developed structure of community/home based palliative care exists in the UK. The intervention would likely be most useful if it was developed in conjunction with those professionals who provide care in this setting. Therefore at the beginning of the project we involved DN's specialist palliative care nurses, GP's, hospice staff, a pharmacist and carers by setting up an advisory group of 12 people. Health professional input was obtained via the advisory group which met five times during the development phase (one year) and eight times in total.

Recruitment of carers

Recruitment of carers via DNs was challenging. A convenience sample of carers was recruited from hospices and one community district. Posters were put up in hospice day centres and nurses attended site and team meetings and were asked to identify carers who met the following criteria: i adult (over 18), ii care(d) for a family member/friend at end of life (defined as last year of life), iii reside(d) with the patient and iv consented to participate in the study. Participants were volunteers recruited via notice boards and by direct approaches from staff. In total 180 information packs for carers were distributed, resulting in the recruitment of 29 carers, of these carers 11 were current carers and 18 were bereaved.

Data collection

All carers took part in semi-structured interviews either in a group or individually. Sixteen carers chose an individual interview and three group interviews were conducted. No demographic details were collected since the aim of the interviews was to explore the problems carers experience(d) in providing care and the knowledge, practical skills and other supports they considered important to provide physical/technical care in the home for their relative/friend at the end of life. In addition the interviews explored the ways and style in which carers preferred to receive information. Each group interview began with a welcome, introductions and an explanation of the study and procedures to be followed concerning confidentiality. The topics covered were as listed above the same as in the individual interviews.

Analysis

Interviews were audio-recorded (with the permission of participants), transcribed and analysed using Framework Analysis, a method often used in health services research to manage open ended data (Ward et al., 2013). This process involved familiarisation, identifying commonalities or themes, indexing and interpretation. Data were managed using the qualitative computer package NVivo 9. The purpose of the analysis was to identify the most common practical nursing problems faced by carers and their other practical concerns whilst caring for somebody in the last weeks of life. We also focused on the comments carers made concerning the medium in which they wished to receive information and the practical issues involved in accessing information. The views of the carers (common problems and issues in accessing information) were presented back to the advisory group and further elaborated upon culminating in an agreed problem list around which evidence based interventions could be formulated.

The intervention

From carer interviews it became apparent that what carers wanted was a single source of information that could be accessed anywhere in the home without reliance on equipment or electronic devices, such as a dvd player, computer or tablet. The following data extracts give some insight into the preferences of the carers:

"I think possibly a video, but definitely a booklet on the things to expect, as a person gets worse with cancer or may be the different aspect of cancer that they may have and what help is available" Hlsh01.

"—Yes for people who have computers, but there are people who don't have computers or are not computer literate. You go on the internet or you go and find out locally, you'll go to the library or you'll send a family member if you are too busy, you need something instant" HscbfgP1.

"I think some sort of carers' booklet would have helped something that would just give you some information, we honestly did not know how to access Macmillan care" Hsbc19.

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