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[1], M. Cooke[1], L. Dunn[1], M. Lloyd-Williams[2], M. Pilling[1], C. Todd[1]

[1] School of Nursing, Midwifery and Social Work, University of Manchester, Oxford Road, Manchester, M13 9PL, UK

[2] 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

Karen.A.Luker@manchester.ac.uk, Mary.Cooke@manchester.ac.uk, Laurie.Dunn@manchester.ac.uk, Mlw@liverpool.ac.uk, Mark.Pilling@manchester.ac.uk, Chris.Todd@manchester.ac.uk

Corresponding Author

Professor Karen Luker
Deputy Director GM CLAHRC
School of Nursing, Midwifery & Social work
University of Manchester
Oxford Road
Manchester M13 9PL

Tel: +44 (0)161 306 0262
Fax: +44 (0)161 306 7867

Acknowledgements

The research team would like to thank the Carers, District Nurses and Advisory Group Members who participated in this study.

Funding

This work was supported by the National Institute of Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0609-19059). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Declaration of Conflicting Interests

None.

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

Abstract

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 I 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 untertaken.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.

Keywords: intervention; cancer; caregivers; practical skills; home-based care; end of life; palliative care

Introduction

Studies of family members’ experiences of caring towards the end of life attest to the physical and psycho-social impact of caregiving (Stajduhar, 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).

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 care giving 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 heath 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. 2009, 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 maybe 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

Whilst carers' preference for a booklet comes as no surprise, although when discussed at the advisory group there was some regret that more elaborate forms of information access were not favoured especially since the budget would extend to multimedia productions. We explored with the carers and professionals on the advisory group whether the booklet should be loose leaved such that carers would only receive information when required, our concern was worrying people unnecessarily about problems that may not occur. The health professionals on the advisory group considered that giving information as required would introduce uncertainty regarding its delivery, especially if the information was to be given out by DNs who may not visit every day, or may not have the relevant paperwork to hand, especially if covering for a colleague. Carers on the advisory group thought that it would give DNs too much control and carers should be allowed to decide what they read. We therefore decided that the intervention would take the form of a single booklet. In terms of the topics/problems covered in the booklet the potential list was wide-ranging, however the most frequently mentioned problems and concerns in the interviews were used as the template and the following topics were incorporated: pain, common bladder problems, common bowel problems, loss of appetite, nausea and vomiting, breathlessness, pressure sores, mobility, equipment, personal care, emotional aspects, support for carers, nearing death and bereavement.

The research team compiled the booklet in a user friendly way in partnership with the professional experts and carers on the advisory group. The format was standardised and agreement reached by consensus at the advisory group meeting such that each topic followed the headings:

- What causes the problem
- How to help
- Common concerns
- Useful resources

The booklet went through three rounds of review and refinement, which involved presenting the booklet to carers and professionals working in palliative care. These reviewers were identified informally by carers and professionals on the advisory group. The final decisions about changes to content and format were made by the advisory group. The booklet was finalised then assessed by the Plain English Campaign and awarded the Crystal Kite Mark, before being published in a high quality format (see online supplementary file for a copy of the booklet).

Evaluating the intervention Phase 2

To evaluate the booklet’s acceptability and utility, our target was a sample was 30 carers. This is considered to be sufficient to gauge acceptability or not of an intervention in a feasibility study (Lancaster et al., 2004).

Recruitment of carers

Carers meeting the criteria outlined in phase one, who were currently caring (not bereaved) for somebody in the last year of life (as estimated by the nurse or GP), at home were our target population. In order to be eligible for the study the patient had to be in receipt of District Nursing services. Carers were recruited via DNs. and meetings were held with DN’s in two community districts; where the study was explained and we asked for volunteers to recruit carers meeting the criteria. The DNs were slow to volunteer despite encouragement from managers and the research team on a weekly basis, so we extended our recruitment to four community districts and one hospice in the North West of England.

The recruitment process for carers was as follows: invitation letters and information packs were left with participating DNs to distribute to carers. Regular contact was maintained with the DNs to monitor carers' circumstances (e.g. death of patient or hospitalization). We also recorded the number of information packs given to DN's to distribute to carers (414 packs in total). If interested in participating carers returned the consent slip in a prepaid envelope to the research team, who then contacted the carer to see if they had any questions and to arrange an appointment to visit the home. For the hospice the process was similar but occurred via the day care facility. In total 26 DNs joined the study and 62 carers were referred via DNs and hospice nurses.

Data Collection

Data collection was based on expected carer outcomes as identified in the literature. The primary outcomes were: increased carer satisfaction, preparedness and competency with caring and decreased report of carer burden. Secondary outcomes were reductions in carer anxiety and depression and improved symptom control (carers' perception). The following well validated and commonly used questionnaires were administered at the first home visit after written consent was given and the researcher had introduced and explained the booklet to the carer.

1. Caregiver burden and satisfaction were assessed using the following questionnaires:

a. The Family Apprisal of Caregiving Questionnaire: positive caregiving subset of 7 items and caregiver strain subset of 8 items (Cooper et al., 2006).
b. Caregiver Competence Scale, a 4 point likert scale (Schumacher et al., 1998);
c. Preparedness for the demands and tasks of caring, 8 items (Archbold et al., 1990);

2. Anxiety and depression were measured using the HADS (Zigmond and Snaith, 1983);

3. Health and wellbeing was assessed with the SF12v2 Health Survey (Medical Outcomes Trust, 2002).

In addition, a single item Likert scale of perceptions of patient symptom management was developed for this study: "I feel I can manage my family member's/friend's symptoms" was completed by the carer. Carers were also given a diary/log to record their use of the booklet and any thoughts they might have had on its usefulness.

Thirty-one baseline data sets were completed but a further 31 carers were non-contactable or withdrew before the baseline data were collected. The reasons for withdrawal before baseline were: could not be contacted on three occasions, away on holiday or changed their mind. After successful completion of the baseline data appointments were made for the researcher to revisit a minimum of four weeks or a maximum of 6 weeks later to collect follow-up data. This time line meant that carers had minimally a month to use the booklet and form an opinion on its utility.

Follow-up data collection carers

Follow-up data using the above questionnaires supplemented by semi-structured interviews of up to 30 minutes were conducted with 24 carers in their home (7 carers withdrew: 5 due to death of patient and 2 for unknown reasons). The interviews focussed on how and when the booklet was used, what was useful and what was not and how the booklet could be improved. The log/diary was collected at this visit, but was only completed by 12 carers.

Follow-up data collection nurses

District nurses who had referred carers to the study were also individually interviewed; in total 14 DNs were interviewed (some nurses had recruited more than one carer). The interviews were brief (approximately 10 minutes) and usually conducted over the telephone because our interest was only in their opinions on the booklet. The interview included questions on how and when the booklet was used, what was useful or not, and how the booklet could be improved. The focus was on the usability of the booklet and the possibility of its integration into everyday practice. All interviews were audio-recoded and transcribed.

Data analysis:

Questionnaire data were analysed using SPSSv20 (IBM Corp, 2011). Questionnaire items were recoded as appropriate for analysis following published manual instructions. Given this was a feasibility study it was not powered to demonstrate statistical significance and analysis of outcome measures concentrated on their estimation pre-intervention and post-intervention (Lancaster et al., 2004). Changes in scores (using paired data) were examined to see whether they lay in the anticipated direction. Normality was assessed using the Shapiro-Wilk test and probability plots. Data were analysed by parametric (t-test) or non-parametric (Wilcoxon signed-rank test), as appropriate, in order to establish whether the difference between baseline and follow-up scores were statistically significant. Both baseline and follow-up scores were compared to the published cut-offs or mean scores.

Each item in the booklet was listed in the diary log and carers were invited to identify their use. These notes and transcripts from the interviews with carers and district nurses were analysed thematically (Boyatzis, 1998). A coding framework of inductive and deductive codes were developed from the interviews with carers, district nurses and the diaries. These codes were then grouped into themes and reported in accordance with the aims of the study. Data were managed using NVivo 9.2.

Findings

Carers were aged 31-82 (mean 62 years old) and cared for people aged 50-92 (mean 70 years old). Eight carers (26%) were male and 23 (74%) were female. Twenty (65%) cared for their partner, 8 (26%) cared for a parent and one cared for a sibling (2 unknown). Only 4 carers were recruited from a hospice.

Interview data were considered alongside quantitative scales in order to gauge the usefulness of the booklet, and the acceptability of the information and the presentation format.

Data were collected at baseline and follow-up (Table 1). The only statistically significant finding related to the 7 item ‘positive caregiving subscale (Cooper et al., 2006).

Insert Table 1 near here

Interview Data: carers

1. Acceptability to family carers

Carers reported a high level of satisfaction and acceptability with the booklet; they highlighted the clear accessible language used, the presentation style, and conciseness. The following quotations demonstrate the booklet’s acceptability to people with limited reading skills:

> *“It's in plain English what you can understand, no fancy words or anything what people don't understand.” SCP27KB*

> *“To me, that’s just right for me to read…because I’m not brilliant, you know”. PC14PC*

The use of clear signposting to appropriate organisations within each section positively contributed to the booklet being user friendly. Other carers summarised their thoughts on the acceptability of the booklet:

> *"It was very useful, I think it puts everything nicely into a context, it's very clear, it gives you what you need without any extraneous information that clouds the issue sometimes and, like I say, it's very practical and straightforward, you can go through those steps and if you're still struggling, you know which professionals are the key ones and it's getting telephone numbers and that, as well, once you've got the number." PC06SW*

Carers also found the practical tips helpful and accessible:

> *"[I like the booklet] because it's handy. And it's not the definitive bible, and that's what I like about it; it's one page, and practical things to do on one page, do you know, so, I'm not trawling through, you know, 2 hours of information to come up with an objective, you know, I can go straight away and try things out there".*

This carer went on to explain:

> *"I like this book, because it goes, 'try this', 'try that', you know, that's the thing I like about it". SM03CH*

Many carers compared the study booklet with other leaflets and booklets that they had encountered during their relative's illness. All carers indicated their preference for the study booklet over other information booklets. The primary reasons for this were again the accessibility and ease of use.

> *"This is probably the one that's in more plain English, you know, and that's what I liked about this, it was easy to read". PC05RG*

> *"Macmillan, they sent me a booklet, which I read that as well, which is very similar in advice for loss of appetite and the way the illness can get worse as it is, yeah.*
>
> *Interviewer: But when you had those questions you looked at that one or did you look at the Macmillan…*
>
> *Respondent: I look at this one… I find it is quite well done actually and it is easy to understand, and there's no flowery messages in it or anything like that. It's just straightforward and simple." SCP28KB*

2. Timing of need for information

A number of issues were raised regarding the optimal time point to provide carers with the booklet. Many carers had some existing knowledge of the topics covered in the booklet, usually gained through prior experiences of being a carer. Whilst 'new' carers found the booklet informative and appropriate, more experienced carers sought more in-depth and specific information. However, these carers generally agreed that the booklet was a good starting point and that it was useful to have all the information and contacts in one place. Other carers said that it would have been beneficial to have had the booklet earlier in the illness trajectory, as they had found out many things through trial and error. In these cases the booklet was less useful in regards to preparedness.

> *"it's a very, very good book, you know, and probably excellent for somebody who has just got into the situation, but when you've been doing it, like, six months, or so, like I've been doing, you, kind of, get into a routine." PC05RG*

The following extract provides a specific example of how the booklet would have been helpful if received earlier:

> *"We were having problems with her taking medication regularly and one thing that I've had done was the blister pack at the chemist, which is mentioned in the book, but I didn't know about that, if I'd have had the book at the beginning, that would have been so much easier to sort things out and it is in the book, but I had already had that done." PC06SW*

A number of carers commented that that they would have liked to have received the booklet at the point of diagnosis so that they could have been better prepared. However, other carers noted that they may not read the end of life sections if they were given the booklet earlier in the illness trajectory, but felt reassured in the knowledge that it was there for them when they were ready to read it as this quotation illustrates:

> *"I've not really thought about that because it's something I don't really want to think about until I know I need to...I like put it at the back of my mind till that actually happens". PC10CG*

By comparison, another carer described how, on coming home from hospital with her husband after they received his diagnosis, she immediately began to look up information on his illness on the internet and with the Macmillan booklet they were given. She explained:

> *"I want to know what's going to happen and I want to know what's going on."*
> *SCP27KB*

The above quotations highlight the differences between individual preferences for information.

Carers suggested a range of possibilities for distributing the booklet; this included directly from the GP or DN, or being freely available to pick up from the GP surgery waiting room or hospice. One carer felt that it was important to build giving out the booklet into standard practice to avoid anyone being missed out.

Carers in this study used the booklet in a variety of different ways; some read the booklet cover to cover, and then referred back to particular sections at an appropriate time. Others chose not to read sections on end of life care, as described above. The findings suggest that giving people information at the beginning of their role in caring for someone with cancer is important, as it allows them to be empowered in how they choose to use it.

3. Views of family carers: caregiver burden, satisfaction, competence, preparedness to care

Overall, carers indicated that the booklet had proved to be a useful resource in providing advice on practical care at home. The findings suggest that the main benefit was that the booklet was an important source of reassurance for carers and helped to increase their confidence in caring.

> *"No-one knows everything, and I knew very little because I was learning. Some things I knew anyway, but it gave me confidence, and reassurance that is maybe the right thing to do, or is the right thing to try, and to, so, yeah, I was quite reassured by it really". SM03CH*

Several carers reported that the booklet was a source of reassurance in regards to common symptoms and symptom management.

> *"[The booklet advised] don't try and force it and don't get upset if they don't eat it. I found that quite comforting because that must mean it's the same for everybody, you know. I might have tended to think, oh is it me, is it because I'm a rotten cook! The booklet sort of said it's quite normal. It's reassuring more than anything, you know, being able to look and be reassured that you're not missing anything or doing anything wrong. That's what I found best". SM02SS*

Reassurance in that these symptoms are common and are experienced by other people with cancer. The following quotation, for example, suggests that this carer may have felt less isolated or alone knowing that others were likely to have similar experiences.

> *"It made you feel that what was happening was what happens when people are poorly…And that I was dealing with it" PC04JN*

The following quotations are also important as they suggest that the booklet widened people's knowledge of what support was available to them. For example, rather than contacting a DN with enquiries, carers suggested they were able to draw on information in the booklet or contact an appropriate organisation that was listed in the booklet.

> *"It was a guide, you see. I saw it as a guide in the right direction for me to use, otherwise I might have got a little bit panicky, and on the phone to the district nurses all the time. So, it did help".SM18HP*

One carer also indicated that the booklet provided her with the confidence to contact appropriate supportive organisations, which had a positive impact on providing care at home.

> *"It didn't feel like, 'I mustn't get other agencies; I ought to do it myself', it made you realise that those agencies are out there, and once you are involved with them, you realise how good they are, how pleasant they are, and how much they want to help you as well as the patient, so I did find that". PC06SW*

> *"It was this confidence backup thing that was really what you get from all the resources that are put in, the fact that you've got your phone numbers there". PC06SW*

The booklet also helped carers with physical and practical aspects of care.

> *"Confirmation that I was doing the things that I knew to be right, and then there was things that I didn't know that I was able to look at and think, "oh yeah"." PC26CG*

A number of participants also described how they found the end of life sections of the booklet useful and reassuring, particularly in regards to preparedness for death.

> *"It was beneficial in a way I was so upset and stressed. I referred to that because I didn't know what was happening with him. I wasn't sure, and I remember you saying the body shuts down. It's nature's way of the way we die, but I was just worried because I thought, is he in pain? Is he aware of it? When I read that book, and it said that probably the person who is caring for them is more stressed than the person who is actually dying. They're probably not aware. So, that helped calm me down quite a lot because I was getting to the point, what can I do, where will I go? It got me like that, but when I read that, I did calm down quite a lot…It was reassuring. Like I say, I used it as a guide, but it did give me a lot of comfort, that part, especially near the end. It was invaluable for me". SM18HP*

Interview Data: DNs

4. Acceptability to DNs and feasibility to adopt into everyday practice

Overall, DNs were very satisfied with the booklet and provided positive feedback. The majority of district nurses believed it would be feasible and worthwhile to incorporate the booklet into their day-to-day practice.

> *"I liked it very much, yeah I thought it was a good book, it covered all the common things that carers need to know about. It was very beneficial I liked it a lot". SMDN21*

The DNs who took part in this study expressed satisfaction with the style, formatting and conciseness of the booklet, which they felt contributed to it being a user-friendly resource for carers.

> *"I thought it was very good, very easy to read. Not a lot of jargon in it is there, you know, for the carer. So the people that I did mention it with and look at it, they, you know, thought it was very useful". BNDN15*

Several district nurses commented on the usefulness of the moving and handling diagrams and pictures of equipment. The nurses explained that it could sometimes be difficult to explain verbally, so it was very useful to have pictures to refer to in addition to their verbal explanation.

> *"I particularly liked the inclusion of the advice about how to move people, you know, how to turn them and transfer them, which is something we do tend to get asked about. And also the photographs of the various equipment they produce, SMDN21*

In addition to these findings, one district nurse suggested that the booklet helped her to see things from a carer's perspective rather than a nursing perspective. She explained:

> *"I think it's made me think more of not just going in as a nurse but, like I said, knowing that the carers have got something there, that somebody's actually interested in them, and they're looking at it from a different angle than from a nursing angle". PC04DN*

Comments from DNs regarding timing and access to the booklet supported comments made by carers. Generally DNs agreed that many carers would benefit from having access to the booklet earlier in the illness trajectory, but noted that this posed organisational challenges; because DNs often become involved with patients in the later stages of the illness when they require help with physical care, or have complex medical needs.

District nurses reported a decline in the number of phone calls they received from clients who were participating in the study. Comments from carers indicated that the booklet acted as a valued source of reassurance; confirming that they were doing the right thing, and helped to answer some of the questions they may have otherwise contacted the district nurse about.

Discussion

This is one of a small number of studies that has been conducted with carers of people who are dying at home and receiving district nursing care. As a feasibility study it was not powered to detect statistical significance, nevertheless there was one statistically significant finding (table 1) and that was in relation to positive caregiving (Cooper et al, 2006). This (positive caregiving) was supported by the interview data, and suggests that the booklet may have the potential to have a positive impact for carers, and district nursing teams by reducing uncertainty and promoting reassurance. This is encouraging, but since this was a feasibility study in order to assess the booklets true impact and potential an RCT is needed and positive caregiving could be a useful outcome measure in this work as could the monitoring of the frequency of telephone calls to DN’s for assistance.

However it is always difficult in palliative care populations to measure positive changes over time and to gauge clinical relevance of findings due to the inevitable deterioration of the patient as they approach death and the consequent anxiety and emotional stress of the carer. A major limitation of this study was that the intervention focussed on support for the provision of physical care. In addition only families in receipt of D.N. services received the booklet and their other needs may have been met by the service hence positively impacting on their opinion of the booklet. Hence the booklet in this study should be seen as an adjunct to the provision of district nursing services.

Leaders in this field have noted the need for well-designed and evaluated supportive intervention studies that focus on addressing caregivers’ needs (Grande et al, 2009). This study makes a contribution to this area of research, as there is a dearth of intervention studies which speak directly to carers’ needs to provide practical nursing care at home. In addition the majority of carers were recruited from community settings rather than a hospice. Despite the difficulties in engaging the participation of D.N’s in the study which we attribute to major structural reorganisations of the service ,their involvement is a key strength of the study, as little research conducted in community settings involves DNs.

The booklet intervention was considered to be of high quality by both carers and nurses. If the booklet was adopted in everyday practice by DNs and GPs it may have the potential to support carers with everyday practical physical care tasks and provide reassurance. It may also reduce the number of telephone calls to DNs and other staff for advice, and may facilitate more people to die at home, for many their place of choice (Gomes et al, 2013).Clearly these assumptions regarding potential benefits would need to be tested in an RCT. The timing is probably optimum for such a trial since facilitating more people to die at home would take pressure off acute hospital beds. The Palliative Care Funding Review in England (Hughes-Hallett, Craft & Davies 2011) suggested that the NHS could make savings of as much as £180 million if palliative care was removed from acute hospitals. Interventions of the kind described here may have a contribution to make in achieving this goal. In addition given the focus worldwide on enabling people to die in their place of choice and avoiding acute hospital admissions at the end of life there is an urgent need to build research and implementation capacity in district nursing services, if further research work is to be undertaken in this increasingly important environment.

There were issues raised by carers on the timing of the delivery of the intervention since it may have had an effect on its usefulness; carers felt that it would have been more useful if they had had the booklet earlier in the illness trajectory. This is difficult to address as community nursing teams may only become involved in a person's care in the latter stages of illness, hence recruiting to the study in this way may be seen by some as a limitation. Conversely, it may be inappropriate to give the booklet to a patient and their family at the time of diagnosis, due to the sections on end of life and bereavement. However thought needs to be given as to whether this intervention could be made available in hospital palliative care clinics or even in hospices.

The booklet contains practical information which was accessible and readable by carers and was reported to be of benefit to them. There is potential to adapt the booklet to make it available to other disease groups beyond cancer and to explore the best route and timing for delivery.

The significant improvement in scores relating to 'positive caregiving' (Cooper et al., 2006) suggests that the booklet may have a measurable positive impact on family caregivers. The booklet provided reassurance for carers of people with cancer; carers' reported that their confidence in caring was raised, the HADS scale was not significant, however the qualitative data does support the notion that the booklet provided reassurance.

Conclusions

This was a feasibility study and it raises practical questions with respect to timing and delivery of the booklet intervention that preclude planning for a large scale trial at this time, which might have been the logical next step. In addition it highlights the importance of working with carers to develop interventions. The booklet intervention was perceived as useful and relevant by carers and DNs (more so than other available media). Such clearly identified practical information which is readable and accessible for carers was of benefit to carers as well as DNs in their role. The combining of semi-structured interviews with quantitative scales permitted us to unravel the importance of reassurance as a potential outcome. This study also demonstrates carers' willingness, even when faced with adversity in this case death, to be involved in research involving the completion of assessment tools. Carers were however reluctant to complete the log/diary and in future work we would omit this as a data collection tool.

This study highlights the difficulties of recruiting through district nursing settings. Recruitment to this study via DNs was difficult, despite great efforts by the research team such as doubling the number of community districts involved and keeping in weekly contact with the nurses. Nevertheless by being persistent we were able to recruit the majority of carers via this route and to achieve the study aims. Recruitment via this route brings its own limitations and the booklet at this stage should be viewed as an adjunct to district nursing care, since having access to a DN could have influenced carers in their evaluation of the booklet.

References

ADAMS, E., BOULTON, M. & WATSON, E. 2009. The information needs of partners and family members of cancer patients: a systematic literature review. *Patient Education and Counseling* [Online], 77. Available: http://www.sciencedirect.com/science/article/pii/S0738399109001487# [Accessed 09/10/2013].

ARCHBOLD, P. G., STEWART, B. J., GREENLICK, M. R. & HARVATH, T. 1990. Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health,* 13**,** 375-384.

BEE, P. E., BARNES, P. & LUKER, K. A. 2008. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing,* 18**,** 1379-93.

BOYATZIS, R. E. 1998. *Transforming qualitative data: Thematic analysis and code development*, Thousand Oaks, CA: Sage.

BURRIDGE, L. H., BARNETT, A. G. & CLAVARINO, A. M. 2009. The impact of perceived stage of cancer on carers' anxiety and depression during the patients' final year of life. *Psycho-Oncology* [Online], 18. Available: http://onlinelibrary.wiley.com/doi/10.1002/pon.1435/pdf [Accessed 09/10/2013].

CAMPBELL, H. S., SANSON-FISHER, R., TAYLOR-BROWN, J., HAYWARD, L., WANG, X. S. & TURNER, D. 2009. The cancer support person's unmet needs survey. *Cancer* [Online], 115. Available: http://onlinelibrary.wiley.com/doi/10.1002/cncr.24386/pdf [Accessed 09/10/2013].

CARESS, A., CHALMERS, K. & LUKER, K. 2009. A narrative review of interventions to support family carers who provide physical care to family members with cancer. *International Journal of Nursing Studies,* 46**,** 1516-1527.

COOPER, B., KINSELLA, G. J. & PICTON, C. 2006. Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psycho-Oncology,* 15**,** 613-622.

CORISTINE, M., CROOKS, D., GRUNFELD, E., STONEBRIDGE, C. & CHRISTIE, A. 2003. Caregiving for women with advanced breast cancer. *Psycho-Oncology,* 12**,** 709-719.

DEPARTMENT OF HEALTH 2008. End of Life Care Strategy- promoting high quality care for all. online: Crown Copyright.

FUNK, L., STAJDUHAR, K., TOYE, C., AOUN, S., GRANDE, G. & TODD, C. 2010. Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008). *Palliative Medicine,* 24**,** 594-607.

GOMES, B., CALANZANI, N., GYSELS, M., HALL, S. & HIGGINSON, I. J. 2013. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* [Online], 12. Available: http://www.biomedcentral.com/1472-684X/12/7 [Accessed 09/05/2014].

GRANDE, G., STAJDUHAR, K., AOUN, S., TOYE, C., FUNK, L., ADDINGTON-HALL, J., PAYNE, S. & TODD, C. 2009. Supporting lay carers in end of life care: current gaps and future priorities. *Palliative Medicine,* 23**,** 339-344.

HARDING, R., EPIPHANIOU, E., HAMILTON, D., BRIDGER, S., ROBINSON, V., GEORGE, R., BEYNON, T. & HIGGINSON, I. J. 2012. What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Supportive Care in Cancer,* 20**,** 1975-82.

HARDING, R. & HIGGINSON, I. J. 2003. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine,* 17**,** 63-74.

HIGGINSON, I. J. & SEN-GUPTA, G. 2000. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine* [Online], 3. [Accessed 05/08/2013].

HODGSON, C., HIGGINSON, I., MCDONNELL, M. & BUTTERS, E. 1997. Family anxiety in advanced cancer: a multicentre prospective study in Ireland. *British Journal of Cancer,* 76**,** 1211.

HUDSON, P. & PAYNE, S. 2011. Family caregivers and palliative care: current status and agenda for the future. *Journal of Palliative Medicine,* 14**,** 864-869.

HUDSON, P. L., ARANDA, S. & HAYMAN-WHITE, K. 2005. A psycho-educational intervention for family caregivers of patients receiving palliative care: a randomized controlled trial. *Journal of Pain and Symptom Management* [Online], 30. Available: http://ac.els-cdn.com/S0885392405003891/1-s2.0-S0885392405003891-main.pdf?_tid=164023d8-30cf-11e3-ba18-00000aab0f01&acdnat=1381315354_48d3152b9117b4c4227c45a68024e511 [Accessed 09/10/2013].

IBM CORP 2011. IBM SPSS Statistics for Windows Version 20.0. Armonk, NY: IBM Corp.

LANCASTER, G. A., DODD, S. & WILLIAMSON, P. R. 2004. Design and analysis of pilot studies: recommendations for good practice. *Journal of Evaluation in Clinical Practice,* 10**,** 307-312.

MEDICAL OUTCOMES TRUST 2002. IQOLA SF-12v2 Standard English (UK) 8/02.

MEDICAL RESEARCH COUNCIL. 2008. Developing and evaluating complex interventions: new guidance. Available: http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC004871 [Accessed 09/05/2014].

SCHUMACHER, K. L., STEWART, B. J. & ARCHBOLD, P. G. 1998. Conceptualization and measurement of doing family caregiving well. *Journal of Nursing Scholarship,* 30**,** 63-70.

STAJDUHAR, K. I. F., L.; TOYE, C.; GRANDE, G. E.; AOUN, S.; TODD, C. J. 2010. Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008). *Palliative Medicine,* 24**,** 573-593.

WIESE, C. H., VOSSEN-WELLMANN, A., MORGENTHAL, H. C., POPOV, A. F., GRAF, B. M. & HANEKOP, G. G. 2008. Emergency calls and need for emergency care in patients looked after by a palliative care team: Retrospective interview study with bereaved relatives. *BMC Palliative Care* [Online], 7. Available: http://www.biomedcentral.com/1472-684X/7/11 [Accessed 09/10/2013].

WONG, R. K., FRANSSEN, E., SZUMACHER, E., CONNOLLY, R., EVANS, M., PAGE, B., CHOW, E., HAYTER, C., HARTH, T. & ANDERSSON, L. 2002. What do patients living with advanced cancer and their carers want to know?–a needs assessment. *Supportive Care in Cancer* [Online], 10. Available: http://link.springer.com/article/10.1007/s00520-002-0354-3# [Accessed 09/10/2013].

ZIGMOND, A. S. & SNAITH, R. P. 1983. The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica,* 67**,** 361-370.

Table 1: Baseline and follow-up scores on core quantitative interview outcome measures

Questionnaire	P	Cut-off/*M*	Mean score baseline	Mean score follow-up	Mean diff [Post-pre] (95%CI)	Interpretation
Positive caregiving subset (Cooper et al 2006, α=0.73)	**0.015**	4.01	4.04	4.23	0.23 (0.05,0.40)	(1-5) Higher=better
Caregiver strain subset (Cooper et al 2006, α=0.86)	0.91	3.17	3.04	3.10	0.01 (-0.18,0.20)	(1-5) Higher=worse
Caregiver Competence Scale (Schumaker et al 1998)	0.27	N/A	1.68	1.58	0.09 (-0.26,0.08)	(1-4) Higher=worse
Preparedness (Archbold et al 1990, α=0.93)	0.21	N/A	2.82	2.98	0.14 (-0.09,0.37)	(0-4) Higher=better
Perception of patient symptom management (Cooke 2011)	0.66†	N/A	3.55	3.75	0.21 (-0.14,0.56)	(1-5) Higher=better
HADS (Zigmond & Snaith 1983)	(A[1]) 0.33† (D[1]) 0.70	(A) 8/9 (D) 8/9	(A) 8.71 (D) 7.77	(A) 8.17 (D) 8.04	(A) -0.54 (-1.96,0.87) (D) 0.25 (-1.06,1.56)	(1-21) Higher=worse
SF12v2 Health Survey (Medical Outcomes Trust 2002)	(P[2]) 0.60 (M[2]) 0.66	(P) 50 (M) 50	51.13 41.49	49.62 42.47	(P) -0.96 (-4.50,2.63) (M) 0.64 (-2.36,3.65)	(0-100) Higher=better

1: A=Anxiety subscale; D=Depression subscale. 2: P=Physical Health subscale; M=Mental Health subscale.
*Median, †Wilcoxon Signed Rank Test