

**Caring at home for a family member with a terminal illness: a qualitative study
of relatives' experiences**

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

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Overview

Caring for a family member with a terminal illness can be highly demanding, and those in this role are at increased risk of poor physical and mental health. Policy guidelines indicate that palliative care services have a key role to play in supporting family caregivers. This thesis explores the emotional challenges faced by relatives caring for a dying family member, and the ways in which healthcare professionals can support them.

Part 1 is a literature review of psychological interventions for caregivers of terminally ill patients. A total of 23 studies were identified for inclusion, and interventions were classified into four types: problem-solving, psycho-educational/supportive, behavioural and bereavement/meaning-based. The majority of the studies reported positive outcomes, but the strength of their designs varied. Overall, the studies provide encouraging evidence for the benefits of psychological interventions in improving some aspects of caregivers' wellbeing.

Part 2 is a qualitative study exploring the emotional challenges faced by home caregivers. Semi-structured interviews were conducted with 15 recently bereaved relatives who had cared at home for a family member with cancer. Transcripts were analysed thematically using the Framework approach and themes were organised under four categories based on Yalom's (1980) existentialist theoretical framework: responsibility, isolation, death and meaningfulness.

Part 3 is a reflective discussion of the process of carrying out the empirical study and the literature review. The limitations of both projects are considered, as well as some of the broader conceptual, methodological, clinical and contextual issues arising from them.

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Part 1: Literature Review

Psychological interventions for relatives caring for a family member with a terminal illness

Abstract

Aims: Relatives caring for a dying family member are at increased risk of poor physical and mental health. Palliative care services have a role to play in supporting carers, and there is growing evidence for the benefits of psychological interventions in this context. This review aimed to critically evaluate this evidence-base and to consider the aims and theoretical approaches of the various interventions.

Method: Studies were identified from existing reviews and a systematic search of the online databases *PsycINFO*, *CINAHL* and *MEDLINE*. The studies included for review were rated for methodological rigour using an adapted version of a checklist developed by Downs and Black (1998).

Results: A total of 23 studies were identified for inclusion. Interventions were classified into four types based on their aims and theoretical approach: problem-solving, psycho-educational/supportive, behavioural and bereavement/meaning-based. The majority of studies reported improvements in aspects of participants' wellbeing following the intervention. Studies varied in terms of their design features, methodological rigour and outcome measures. The most robust evidence was for problem-solving interventions; other intervention types also showed promise.

Conclusions: Overall, the studies provide encouraging evidence for the benefits of psychological interventions for caregivers of terminally ill patients. Further research is needed to explore the optimum format and timing of interventions, their long-term effects after bereavement, and the suitability of particular approaches for specific groups and individuals. Such research should go hand-in-hand with consideration of the role of professionals in palliative care settings, and the development and refinement of national and local policy guidelines.

Introduction

Caregiving at the end of life

The relatives and informal carers of people with a terminal illness often face numerous practical and emotional challenges towards the end of their family member's life. Research suggests that family carers often feel unprepared for the role, which may come with a complex array of new responsibilities and major lifestyle changes (Hebert, Dang, & Schulz, 2006; Hebert, Schulz, Copeland, & Arnold, 2009). Being a carer can feel burdensome and overwhelming (Phillips & Reed, 2009), especially when decisions must be made about a patient's care or treatment (Radwany et al., 2009). Carlander, Sahlberg-Blom, Hellström and Ternestedt (2011) found that caring can be experienced as both meaningful and deeply unsettling, as relatives face situations that challenge their own self-image. In addition to managing their caregiving responsibilities, relatives must try to come to terms with the imminent death of their family member. Caregivers frequently report feelings of powerlessness (Milberg, Strang & Jakobsson, 2004), hopelessness (Sullivan, 2003) and insecurity (Funk, Allan, & Stajduhar, 2009); they may even experience the pre-loss period as more stressful than the period after bereavement (Johansson & Grimby, 2012). Studies have shown that caregivers are at increased risk of poor psychological and physical health (Chentsova-Dutton et al., 2000; Grov, Dahl, Moum, & Fosså, 2005; Hudson, Thomas, Trauer, Remedios, & Clarke, 2011), social isolation (Chentsova-Dutton et al., 2000) and financial strain (Saunders, 2009).

It is important to note, however, that relatives may also experience positive aspects to caregiving (Andershed, 2006; Milberg & Strang, 2003; Wong, Ussher, & Perz, 2009). Caregiving can create opportunities for strengthening and deepening

relationships, and for some patients and relatives this may be a time of reconciliation, love and even personal growth (Wong et al., 2009; Yalom, 1980).

Professional caregiving

In the UK, end-of-life or “palliative” care is provided by a range of healthcare services and in a variety of settings including hospitals, hospices, care homes and patients’ own homes. In policy guidelines, effective collaboration with relatives and carers is enshrined as a key principle of end-of-life care (National Institute for Clinical Excellence, 2004; Department of Health, 2008). In addition, it is widely acknowledged that relatives have their own unique needs, which professionals should seek to address regardless of the patient’s condition (Department of Health, 2008; Hudson & Payne, 2011). In fact, it may be difficult to separate out the needs of patients and caregivers. Many of the factors identified by patients as important at the end of life concern the people close to them: for example, resolving conflicts, being able to say goodbye, having family present and being able to talk to and trust professionals (Steinhauser et al., 2000a; 2000b). Similar factors are also often cited by family caregivers (Boucher et al. 2010; Steinhauser et al., 2000a; 2000b).

There is also some evidence that relatives’ experiences during end-of-life care can affect their coping during bereavement. Relatives who feel confident that a service has done everything possible for their family member are less likely to experience feelings of resentment and guilt (Grande et al. 2004; Radwany et al., 2009; Ylitalo, Valdimarsdóttir, Onelöv, Dickman, & Steineck, 2008). In contrast, perceptions of professional error or inadequate care, and feeling unprepared for the death, are associated with poorer post-loss adjustment (Barry, Kasl & Prigerson, 2002; Carr, 2003; Carr, 2009; Field & Bonanno, 2001; Hebert, Schulz, Copeland, & Arnold, 2008). These considerations lend further weight to the argument that

palliative care should extend to relatives and informal carers, as well as the patients they are caring for.

Interventions for carers

Despite growing appreciation of carers' needs during end-of-life care, current guidelines offer little advice on how professionals can support them in practice (Hudson, Zordan, & Trauer, 2011), and there is evidence to suggest that carers' needs often go unmet (Soothill et al., 2003). In the UK, there are high rates of complaints pertaining to end-of-life care (Department of Health, 2008) and recent figures suggest that many carers still feel inadequately supported (Department of Health, 2012b). Hudson and Payne (2011) argue that, internationally, support for caregivers in palliative care suffers on account of poor funding, lack of dedicated resources, insufficient staff training and low staff confidence.

There is, however, a small but growing evidence base for the merits of supportive interventions for caregivers at this time. Three systematic reviews of interventions for carers in palliative care have been published in the last few years (Candy, Jones, Drake, Leurent, & King, 2011; Harding, List, Epiphaniou, & Jones, 2012; Hudson, Remedios, & Thomas, 2010). Candy et al. (2011) carried out a meta-analysis of randomised controlled trials (RCTs), identifying 11 studies evaluating practical and emotional interventions for caregivers. They concluded that there is limited evidence supporting the efficacy of interventions to reduce short-term caregiver distress. Because of the variability of the interventions and the paucity of high quality research, the authors were unable to draw conclusions regarding the relative efficacy of different interventions and effective modes of delivery.

Hudson et al. (2010) and Harding et al. (2012) carried out broader reviews including non-randomised studies, building on an earlier review by Harding and

Higginson (2003). Both found that the majority of studies had favourable outcomes but, again, there was a high degree of variability in the nature of interventions and the outcomes measured. Hudson et al. (2010) concluded that research in the field remains in its infancy, making it difficult to implement broadly sketched policy guidelines without a sufficient evidence-base.

In sum, the evidence-base for supportive interventions for caregivers is of a rather patchy nature, consisting of a variety of intervention types ranging from yoga to music therapy to psycho-education to group counselling. The quality of the evidence is variable and few conclusions have been drawn about the relative merits of different approaches. Questions about the appropriate timing and length of interventions remain unanswered.

How we interpret this state of affairs is a matter open to dispute. One could argue that generic, manualised approaches simply do not work in a field where care is, and must always be, highly personalised. A report published in 2008 by the British Psychological Society (BPS) recognises a role for clinical psychologists in end-of-life care, which includes supporting carers before and after bereavement (BPS, 2008). The report encourages psychologists to take an “individualised approach”, drawing on generic skills of assessment, formulation and intervention. The role of “caregiver” is not neatly defined and this begs the question of whether it is even appropriate to class carers together as a kind of pseudo-patient group.

On the other hand, the absence of clearly defined theoretically derived interventions, and the potential for conflicting or inconsistent approaches, creates the risk of carers’ needs going unmet. Several authors comment critically on the frequent lack of theoretical underpinnings of research into relatives’ experiences of end-of-life care (Downey, Curtis, Lafferty, Herting, & Engelberg, 2010; Funk et al., 2010).

Again, there may be a danger that the complexity of individuals' experiences are diluted by theorisation, but, equally, theory may provide a helpful framework for health care professionals seeking to recognise, understand and respond to relatives' needs.

In addition, it would be dangerous to assume - especially at a time of resource constraints - that any kind of support is bound to be helpful. Research into bereavement, for example, has found that routine provision of therapy to enhance adaptation is not universally beneficial and may even disrupt normal grieving processes. The recommendation is that interventions are targeted towards those who experience, or are at risk of experiencing, complicated or adverse grief reactions (Schut & Stroebe, 2005). As in bereavement, caregivers' experiences during end-of-life care are highly varied and changeable over time (Nijboer et al., 2000). This raises questions about when and how palliative care services should be offering interventions and how they might complement or jar with caregivers' own coping mechanisms.

The current review

The purpose of this review is to summarise and critically evaluate the evidence-base for psychological interventions for caregivers of terminally ill patients. It is an update and extension of the existing reviews described above and also differs from them in several important respects (see Table 1).

In contrast to the broad inclusion criteria of Harding et al. (2012), this review examines only studies evaluating psychological/psychosocial interventions. It excludes studies evaluating services as a whole, interventions consisting primarily of practical support or respite, and "alternative" interventions such as yoga and music therapy. The rationale was to evaluate a more homogenous set of studies adopting a

primarily talking-based approach. (It was also anticipated that alternative approaches are less likely to be widely used in services due to the specialist personnel required.) In addition to evaluating the quality of the research, this review will consider the extent to which interventions are rooted in relevant theory and the range of theoretical approaches drawn on within the literature.

This review also focuses specifically on the end-of-life period. Unlike Harding et al. (2012), it excludes interventions for caregivers of patients with early-stage cancer; again, this was with a view to conducting a detailed synthesis of a more homogenous set of studies. Finally, unlike Candy et al. (2011), this review includes studies with non-randomised and single-group designs. Although of a less robust nature, evidence from such studies may still be informative, especially in the earlier stages of intervention development.

In summary, the review aimed to address the following questions:

1. What psychological interventions have been developed for caregivers of terminally ill patients and what is the evidence for their effectiveness?
2. What theoretical frameworks do interventions draw on?
3. What are the implications for research and clinical practice?

Table 1: Recent reviews of interventions for carers of patients with a terminal illness

Review	Period covered	Types of interventions included	Timing of interventions	Types of studies included	Main difference from current review
Candy et al. (2011)	Studies published before May 2010	Practical, psychological and patient-focused interventions.	End-of-life period only	RCTs only	Included only RCTs and looked at a broader range of intervention types.
Harding et al. (2012)	2001-July 2010	Practical, psychological and patient-focused interventions and service-evaluation studies.	End-of-life period and earlier-stage cancer.	RCTs, quasi-experimental studies, uncontrolled trials and qualitative studies.	Included a broader range of intervention types, including interventions targeting caregivers of patients with non-terminal cancer.
Hudson et al. (2010)	January 2000-July 2009	Psychosocial and psycho-educational interventions	End-of-life period only	RCTs, quasi-experimental studies, uncontrolled trials and qualitative studies.	Did not compare intervention approaches; 2009 cut-off date.

Method

Search strategy

Studies were identified from the existing reviews of Hudson et al. (2010), Candy et al. (2011) and Harding et al. (2011), an electronic database search of additional studies published since 2010 (which marked the latest publication date for studies included in the three previous reviews) and citation-searching of key studies.

The electronic databases *PsycINFO*, *CINAHL* and *MEDLINE* were searched. A combination of the search terms used by Harding et al. and Hudson et al. were used to ensure all relevant studies were identified (the search strategy employed by Candy et al. took a different approach employing large numbers of search terms adapted for each database). Some of the terms also included by Hudson et al. (e.g. “grief”) were not used as they yielded large numbers of irrelevant studies. The final search employed following combinations of keywords: (*carer* OR caregiver**) AND (*support OR intervention OR therapy*) AND (*palliative OR terminal OR end of life OR hospice*). The search output was filtered to include only papers published between January 2010 and June 2012. Only papers appearing in peer-reviewed journals and published in the English language were considered for inclusion.

Inclusion and exclusion criteria

Inclusion criteria were: (1) An evaluation of a psychological intervention aimed at supporting informal caregivers of adult patients with a terminal illness (“psychological intervention” was operationalised broadly to include any intervention using a talking-based approach and seeking to improve some aspect of caregivers’ psychological or emotional wellbeing); (2) study design one of the following: randomised control trial (RCT), uncontrolled trial or quasi-experimental design; (3) the inclusion of at least one quantitative evaluation measure.

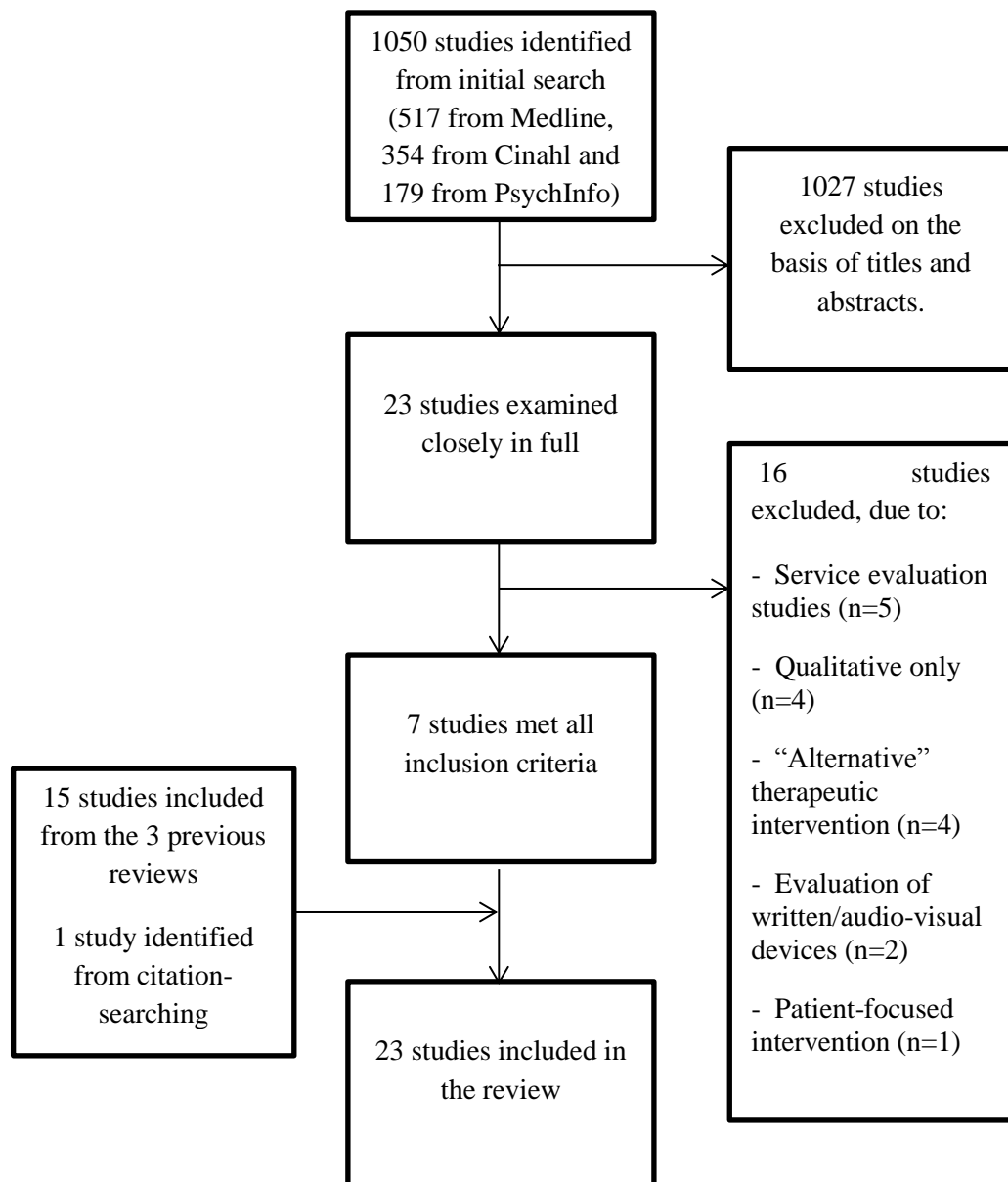
Exclusion criteria were: (1) studies employing qualitative methods only; (2) studies evaluating patient-focused rather than caregiver-focused interventions; (3) studies evaluating “alternative” interventions such as yoga and music therapy; (4) service evaluation studies; (5) studies evaluating interventions for caregivers of patients with non-terminal illnesses or where prognosis was unclear (e.g. early stage cancer).

Study selection

Figure 1 shows the study selection process. A total of 39 studies were identified from the three previous reviews once duplicates had been removed. Of these, 15 met inclusion criteria for this review. The types of studies and interventions excluded were: service evaluation studies (n=8); patient-focused interventions (n=3); interventions for caregivers of patients with non-terminal illnesses (n=5); interventions employing “alternative” therapeutic approaches (n=3); studies employing qualitative methods only (n=2); studies evaluating provision of respite breaks for carers (n=2) and studies evaluating the use of written materials (n=1). Where eligibility was unclear, studies were discussed among the research team and a consensus reached.

A total of 1050 studies were returned from the search of electronic databases. Studies were first screened by titles and abstracts to compile a list of 23 potentially eligible studies, the manuscripts of which were examined in full. The vast majority of studies were excluded at this first stage because they were not evaluations of interventions. Seven of the 23 short-listed studies met all the inclusion criteria. A further one study was identified through citation-searching, bringing the total number of studies included in the review to 23.

Figure 1: Study selection flowchart



Quality ratings

Studies were rated for their quality using a checklist developed by Downs and Black (1998) and adapted by Cahill, Barkham and Stiles, (2010). Cahill et al. modified the original checklist for use in their systematic review to make it more applicable to practice-based evidence. Their version is more appropriate to this set of studies, where small scale hospice-based studies predominated over large-scale efficacy trials. In a pilot study by Downs and Black (1998) it was found to have high internal consistency and good test-retest and inter-rater reliability.

The checklist comprises 32 items, covering a range of quality criteria. For each item, studies are given a score of one if they meet the criterion and a score of zero if they do not (or if it is not possible to determine). Guidelines are given by the authors on the basis for assigning scores. Where any ambiguity arose in the interpretation or scoring of items this was discussed among the research team. An operational definition of the item was then decided on and applied consistently across the study set. The checklist yields an overall score and scores for four separate quality indices: (1) reporting; (2) external validity; (3) internal reliability; (4) internal validity – confounding (selection bias). It has the advantage that studies can be compared for their strengths and weaknesses in these four domains.

Data extraction

Data were extracted from the published papers for each study. Effect sizes are given where reported by the authors or where sufficient data was provided to enable their calculation. Due to the plethora of different outcome measures used in this set of studies, for ease of comparison the main outcome variables are reported rather than the specific measures used.

Results

Categorisation of studies

Studies were classified according to the nature and purpose of their interventions, as shown in Table 2. In contrast to Harding et al.'s (2012) classificatory system, the focus here is on the theoretical underpinnings and aims of the interventions rather than their extrinsic properties (e.g. individual vs. group format). The aim in classifying was to capture the main thrust of an intervention, not to exhaustively characterise all its elements.

Table 2: Nature and aims of interventions

Intervention type	Description	Number of Studies
Problem solving	Interventions which aimed to improve caregiver coping by teaching problem-solving skills and techniques.	6
Psycho-educational/ supportive	Interventions which aimed to inform or guide caregivers on issues relevant to their role such as patient symptoms, the services available to them, and self-care.	11
Behavioural	Interventions which focused primarily on teaching caregivers behavioural skills and techniques such as patient pain management.	2
Bereavement/meaning-based	Interventions which focused on helping caregivers find meaning in their role, gain a sense of closure and/or come to terms with the approaching death of their relative.	4

Table 3 summarises extrinsic features of the interventions in terms of their delivery format and duration. Table 4 presents details of the 23 studies, categorised by intervention type according to the typology above.

Table 3: Extrinsic features of the interventions

Feature	Number of Studies
<i>Format of intervention</i>	
Individual face-to-face	7
Individual via telephone/videophone	4
Patient-carer dyad face-to-face	3
Family group face-to-face	3
Carer group face-to-face	6
<i>Intended duration</i>	
Single session	5
2-3 sessions	11
4-6 sessions	6
7 or more sessions	1

Table 4: Description of individual studies

Author (date)	Intervention	Theoretical underpinnings	Delivered by	Design and assessment points	Sample	Outcome variables	Results
Problem-Solving Interventions							
Cameron et al. (2004)	1 hour face-to-face problem-solving intervention. Participants were taught a 5-step problem-solving technique and introduced to the COPE model.	Lazarus & Folkman's (1984) stress appraisal and coping theory; the COPE model (Houts et al., 1996) - be Creative, Optimistic, Plan and obtain Expert information.	Research assistant	Uncontrolled trial. Baseline assessment and 4-week follow-up.	58 caregivers of patients with advanced cancer living at home. Analysis based on 34 participants who completed intervention.	Problem-solving; Emotional Wellbeing; Assistance Needs; Self-Efficacy	Reductions in emotional tension at follow-up. Non-significant trends for improved caregiving confidence and positive problem-solving orientation.
Demiris et al. (2010)	3 sessions of individual face-to-face problem-solving training. Intervention based on the ADAPT model (see above)	D'Zurilla & Nezu's (2007) ADAPT model: cultivate a positive Attitude, Define the problem, develop Alternative solutions, Predict their outcomes and Try out the best option.	Research coordinator	Uncontrolled trial (feasibility study). Assessment at baseline and 1 week post-intervention.	29 caregivers of patients newly admitted to community hospice services. 23 participants completed the intervention.	Quality of Life (QoL); Problem Solving; Anxiety; Reactions to Caregiving; Qualitative Feedback	Small sample size limited analysis: non-significant improvements in problem-solving skills and QoL, decreased anxiety and negative impact of caregiving.
Demiris et al. (2011)	3 sessions of problem-solving training delivered via video-phone. Intervention based on the ADAPT model.	ADAPT model (D'Zurilla & Nezu, 2007).	Nurse/Social worker	Uncontrolled trial (feasibility study). Assessment at baseline and a few days post-intervention.	42 caregivers of patients newly admitted to community hospice services. 38 participants completed the intervention.	Quality of Life; Problem Solving; Anxiety	Reductions in anxiety ($d = 0.25$) and approach-avoidance conflict ($d = 1.08$). Trend for improved QoL and problem-solving confidence.

Table 4 Continued

Author (date)	Intervention	Theoretical underpinnings	Delivered by	Design and assessment points	Sample	Outcome variables	Results
Demiris et al. (2012)	3 sessions of problem-solving training delivered either face-to-face or via video-phone. Intervention based on ADAPT model.	ADAPT model (D’Zurilla & Nezu, 2007).	Nurses/social workers with hospice experience and prior training.	Randomised “non-inferiority trial”: randomised assignment to face-to-face or videophone groups.	126 hospice caregivers; 89 caregivers complete the study.	Quality of Life; Problem Solving; Anxiety	Reductions in anxiety and improvements on some dimensions of problem-solving ability. No differences between intervention groups.
McMillan et al. (2006)	Problem-solving intervention delivered in 3 visits. Intervention was based on the COPE model and focused on helping caregivers effectively manage patients’ symptoms.	Literature on problem-solving training, including the COPE model.	Nurses with hospice experience who attended a 4-day training course.	3-group RCT: randomised assignment to standard care, standard care + non-specific emotional support or intervention group. Baseline assessment, 1 and 2-week follow-up.	354 caregivers of patients with advanced cancer receiving home hospice care. 329 participants completed intervention, 30% of participants provided 2 week follow-up data.	Quality of Life; Caregiver Burden; Mastery; Caregiving Demands; Coping	Intervention group showed greater improvement in QoL (10%) and reduction in burden of patient symptoms (30%).
Meyers et al. (2011)	Problem-solving intervention for patient-carer dyads comprising 3 face-to-face sessions. Intervention based on the COPE model and included a written guide.	Literature on problem-solving training and therapy, including the COPE model (Houts et al., 1996).	Health educators trained by an expert in the COPE model	Multi-site RCT. Participants randomised to intervention and standard-care control groups. Assessments at baseline and 1, 2, 3, 4 and 6 month follow-up.	476 patient-carer dyads. Patients were newly enrolled on drug trials and had advanced cancer.	Quality of Life; Problem-Solving	QoL decreased in both groups but at less than half the rate in intervention group, consistent with a “moderate” clinical significance.

Table 4 Continued

Author (date)	Intervention	Theoretical underpinnings	Delivered by	Design and assessment points	Sample	Outcome variables	Results
Psycho-educational/supportive interventions							
Hannon et al. (2012)	A one-off family meeting with members of the hospice multidisciplinary team focusing on family members' needs and concerns.	Not stated	Medical social worker and other palliative care professionals.	Uncontrolled trial. Assessments pre- and post-meeting and 48hour follow-up.	31 family members of patients admitted to hospice. 28 participants provided complete data.	Met/unmet needs; Tailored evaluation measure.	Increased proportion rating care needs as "met" across a number of domains, sustained at follow up.
Harding et al. (2004)	Structured group intervention comprising 6 weekly sessions. Aimed to promote caregiver self-care through informal education and emotional support.	Intervention was informed by a review of the literature on carers' needs and a prior qualitative study.	One group facilitator + weekly speakers from different professions.	Quasi-experimental design: intervention group compared to controls who declined intervention. Assessments at baseline, post-intervention and 4 month follow-up.	73 carers of patients attending a home palliative care service. Complete data obtained from 26 participants.	Palliative care outcomes; Burden; Coping; Psychological distress; Anxiety.	No effects observed on outcome measures, but participants gave positive qualitative reports, valuing opportunities for mutual sharing/peer support and learning from professionals.
Henriksson et al. (2012)	Structured caregiver group intervention comprising 6 weekly sessions involving presentations from various professionals.	Intervention was informed by a review of the literature on carers' needs, staff experience and a prior qualitative study.	Two hospice nurses + weekly speakers from different professions.	Quasi-experimental design: intervention group compared to non-equivalent control group. Assessments at baseline and 7 week follow-up.	125 caregivers of patients receiving palliative care (inpatient and outpatient). 95 participants provided complete data.	Preparedness; Perceived Competence; Caregiving Rewards; Anxiety; Depression; Hope; Health	Improvements in caregiver preparedness (d=0.65), competence (d=0.30) and rewards (d=0.18).

Table 4 Continued

Author (date)	Intervention	Theoretical underpinnings	Delivered by	Design and assessment points	Sample	Outcome variables	Results
Hudson et al. (2005)	2 individual sessions + a telephone call. Multiple aims including providing information, promoting self-care and enhancing positive meaning-making.	Lazarus & Folkman's (1984) stress appraisal and coping theory	Palliative care nurses	RCT: randomised assignment to standard care or intervention group. Assessments at baseline, 5 week follow-up and 8 weeks after the patient's death.	106 Caregivers of cancer patients receiving palliative home care. Analysis based on 75 participants who provided pre/post data.	Preparedness; Perceived Competence; Caregiving Rewards; Anxiety; Depression; Self-Efficacy	Participants in the control group reported less caregiver rewards, whilst scores for those in the intervention group increased slightly ($d = 0.11$).
Hudson et al. (2008)	A psycho-educational group comprising 3 semi-structured 90 minute sessions, designed to help caregivers prepare for their role. Sessions focused on (1) the role of the carer; (2) self-care and patient care; (3) preparing for the death.	Lazarus & Folkman's (1984) stress appraisal and coping theory.	Members of the hospice multi-disciplinary team who completed a short training programme.	Uncontrolled trial (feasibility study). Assessments at baseline, post-intervention and 2 week follow-up.	74 caregivers of patients newly admitted to home-hospice services. Complete data obtained from 44 participants.	Perceived competence; Preparedness; Met/unmet needs; Caregiving rewards; Perceived social support; Burden/impact of caregiving; Optimism.	Improvement in self-reported preparedness ($\eta^2=0.21$), competence ($\eta^2=0.17$), rewards ($\eta^2=0.09$) and having information needs met ($\eta^2=0.09$). Increases seen in caregiver distress.
Hudson et al. (2009)	As described in Hudson et al. (2008)	Lazarus & Folkman's (1984) stress appraisal and coping theory	Members of the hospice multi-disciplinary team who completed a short training programme.	Uncontrolled trial (implementation of 2008 pilot study with larger sample). Assessments at baseline, post-intervention and 2 week follow-up.	156 caregivers of patients receiving home-based palliative care. Complete data obtained from 96 participants.	Perceived competence; Preparedness; Met needs; Caregiving rewards; Qualitative feedback	Improvements in preparedness ($\eta^2=0.3$), competence ($\eta^2=0.14$), rewards ($\eta^2=0.12$) and information needs met ($\eta^2=0.12$).

Table 4 Continued

Author (date)	Intervention	Theoretical underpinnings	Delivered by	Design and assessment points	Sample	Outcome variables	Results
Hudson et al. (2009b)	A one-off family meeting focused on caregivers' needs and based on clinical practice guidelines previously drawn up by Hudson et al. (2008).	Lazarus & Folkman's (1984) stress appraisal and coping theory; Talmon's (1990) Single Session Therapy; Family Consultation Model (e.g. Marsh, 1998).	Trained Palliative Care Nurses	Uncontrolled trial. Assessments pre- and post-meetings + 48hour follow-up.	20 caregivers of patients with advanced cancer referred to an inpatient hospice, 4 patients and 18 professionals.	Met/unmet needs; Tailored evaluation measure and qualitative data.	Improvements in care needs met, maintained at follow-up ($\eta^2 = 0.43$).
Hudson et al. (2012)	A single, 1.5 hour didactic group intervention focusing on 5 topics: (1) what is palliative care? (2) role of caregivers; (3) support services; (4) preparing for the future; (5) self-care.	Lazarus & Folkman's (1984) stress appraisal and coping theory	Palliative care nurses and research assistants who attended a 1 day training course.	Uncontrolled trial (feasibility study). Assessments at baseline and 3 days post-intervention.	15 Caregivers of patients newly admitted to an inpatient hospice. Complete data obtained from 13 participants.	Met/unmet needs; Psychological wellbeing; Preparedness; Perceived Competence	Improvements in self-reported preparedness.
Kilbourn et al. (2011)	10-12 weekly telephone counselling calls. Calls were semi-structured and focused on a range of topics including coping, problem-solving and grief/loss.	Theoretical basis not stated, but intervention appears to draw on multiple theoretical frameworks.	Trained Masters level counsellor.	Uncontrolled trial (feasibility study). Assessment at baseline, 3 and 6 month follow-up.	25 carers of home hospice patients. 19 participants completed the intervention.	Depression; Perceived Stress; Social Support; Quality of Life; Perceived benefits to caregiving.	Small sample size precluded analysis but depression and perceived stress decreased and social support, emotional/social quality of life and benefit finding increased.

Table 4 Continued

Author (date)	Intervention	Theoretical underpinnings	Delivered by	Design and assessment points	Sample	Outcome variables	Results
Walsh & Schmidt (2003)	A telephone intervention designed to meet caregivers' needs for comfort, control and communication. Participants received 4 weekly calls of 1 hour's duration.	Hogan's Model of Bereavement (e.g. Hogan, Morse & Tason, 1996).	Nurses	Uncontrolled trial. Assessment at baseline and in the days following last session of intervention.	14 caregivers of hospice patients were recruited but only 5 were able to complete the intervention before the patient's death.	Caregiver Burden; Depression; Perceived Social Support; Grief reactions; Qualitative evaluation.	Small sample size precluded analysis but decreases in caregiver depression, disorganisation and despair were observed. Caregiver burden increased.
Walsh et al. (2007)	6 weekly visits involving comprehensive assessment of needs, advice, information and emotional support. Up to 6 visits continued to be offered even if the patient died.	Intervention was based on findings from a prior survey of caregivers' preferences for additional support.	Carer advisors with experience in nursing and social care and who completed a 1 month training course.	RCT. Participants randomised to intervention or control group receiving standard care. Assessment at 4, 9 and 12 weeks and 4 months post-bereavement.	271 caregivers of patients admitted to home-hospice care and scoring above threshold on the General Health Questionnaire (GHQ).	Psychological Wellbeing; Caregiver Strain; Quality of Life; Bereavement Outcomes; Qualitative feedback.	One third of participants in both arms fell below threshold on the GHQ. GHQ scores were lower among controls but differences were not significant.
Behavioural Interventions							
Carter (2006)	A brief behavioural sleep intervention incorporating stimulus control, relaxation, sleep hygiene and cognitive therapy. Comprised 2 sessions, 4 weeks apart.	Cognitive behavioural treatments for insomnia. Authors also cite evidence that sleep quality affects appraisals and subjective wellbeing.	Masters level nurses who completed a half-day's training in the sleep intervention.	RCT: participants randomised to intervention or control group who received training on back health. Assessment at various time-points up to 4 months later.	36 caregivers of patients with advanced cancer living at home. Caregivers had sleep difficulties.	Sleep quality (measured subjectively and objectively); Depression; Quality of Life.	Improvements in depression, sleep and quality of life in both groups. Some evidence for greater improvement in intervention group at certain time points.

Table 4 Continued

Author (date)	Intervention	Theoretical underpinnings	Delivered by	Design and assessment points	Sample	Outcome variables	Results
Keefe et al. (2005)	Patient and caregiver dyads received three sessions of pain management training, as well as a videotape and accompanying book.	Cognitive-behavioural approaches to pain management.	Experienced nurse educators, trained in delivering coping skills interventions.	RCT. Participants randomised to intervention or control group who received standard care. Assessment at baseline and 1 week post-intervention.	78 patient-carer dyads. Patients had advanced cancer. Complete data obtained from 56 participants (28 in each group).	Self-Efficacy in controlling pain; Caregiver Strain; Mood.	Intervention group showed higher self-efficacy for managing pain ($d=0.79$) and other symptoms ($d=0.71$) than controls.
Bereavement/meaning-based interventions							
Allen et al. (2008)	Family-focused intervention involving 3 home visits. Patient-caregiver dyads constructed a visual/auditory record of positive memories/values.	Lazarus & Folkman's (1984) stress appraisal and coping theory, Socio-emotional selectivity theory (Carstensen, 1993) and life review therapy.	Masters level Psychology and Social Work graduates who received "intensive training".	RCT. Participants randomised to intervention group or control group who received 3 supportive telephone calls. Assessments at baseline and 1 week post-intervention.	42 patient-carer dyads recruited from local health services. Patients had a life-limiting illness. Complete data obtained from 31 dyads.	Psychological wellbeing; Physical symptoms; Religion and Spirituality; Depression; Perceived stressors.	Caregivers who received the intervention showed reductions in stress, controls showed increases ($\eta^2=0.15$).
Duggleby et al. (2007)	Single home visit in which caregivers were shown a video and taught a journaling activity.	"Hanging on to Hope" – a theory developed based on previous research by the authors.	Trained nurses.	Single group pre-test/post-test design. Assessments at baseline, 1 and 2 weeks post-intervention.	10 family caregivers of patients with advanced cancer receiving palliative home care.	Hope; Quality of Life; Qualitative Feedback	Small sample size precluded analysis but some improvements in hope and QoL were observed.

Table 4 Continued

Author (date)	Intervention	Theoretical underpinnings	Delivered by	Design and assessment points	Sample	Outcome variables	Results
Kissane et al. (2006)	“Family Focused Grief Therapy”. Therapy commenced prior to the patient’s death and consisted of 4-8 family therapy sessions of approximately 90 minutes’ duration.	Family Focused Grief Therapy (Kissane et al., 2002); McMaster model of family functioning (Epstein et al., 1983).	Social workers who were qualified family therapists and received 2 half-days of training and expert supervision.	Multi-site RCT. Participants randomised to intervention group or control group who received standard care. Assessments at baseline and 6 & 13 months after bereavement.	81 at-risk families of home-hospice patients with terminal cancer. 40/53 participants in the intervention arm completed therapy.	Psychological Distress; Depression; Adjustment; Family functioning; Bereavement outcomes.	Findings were mixed. Families with highest baseline distress showed reductions in depression ($d = 0.44$) and distress ($d=0.32$).
Kwak et al. (2007)	“Caregiving at Life’s End” programme. Structured group programme of 5 x 90 minute sessions involving a range of exercises, discussion topics and readings. Programme aimed to help caregivers find meaning in their role and gain a sense of closure.	The Hospice Experience Model of Care (Egan & Laybak, 2005).	A range of professionals who attended a 5-day training workshop ($n = 142$)	Uncontrolled trial. Assessments at baseline and immediately after last session of intervention.	2025 family caregivers from a range of settings received the intervention, 926 provided complete data.	Comfort with caregiving; Sense of closure; Sense of satisfaction.	Improvements in caregiver comfort (16%), closure experiences (11%) and caregiver gain (7%).

Overall study quality

Table 5 summarises the methodological characteristics of the studies in terms of design type and length of follow-up. Table 6 displays scores for each study on the four quality domains of the Cahill et al. (2010) checklist, and means and ranges across the study set. Important for interpreting these scores is the fact that the 32 items in the checklist are not evenly distributed across the four domains, so the indices have different total scores. These are specified in the table.

Table 5: Methodological characteristics of the studies

Design feature	Number of Studies
<i>Design type</i>	
Randomised control trial	9
Quasi-experimental design	2
Uncontrolled trial	12
<i>Length of follow-up after intervention</i>	
Up to 1 week	11
2 weeks	4
3-4 weeks	1
5 weeks - 4 months	3
5-6 months	3
Longer than 6 months	1

Table 6: *Quality ratings of the studies*

Study	Reporting (total = 11)	External validity (total=11)	Internal reliability (total= 5)	Internal validity - confounding (total=5)	TOTAL SCORE (total=32)
Problem-solving interventions					
Cameron et al. (2004)	11	5	3	1	20
Demiris et al. (2010)	9	3	3	0	15
Demiris et al. (2011)	9	3	3	0	15
Demiris et al. (2012)	8	4	5	4	21
McMillan et al. (2006)	8	5	5	4	22
Meyers et al. (2011)	8	4	5	5	22
Psycho-educational/supportive interventions					
Hannon et al. (2012)	10	5	3	2	20
Harding et al. (2004)	10	4	5	2	21
Henriksson et al. (2012)	9	5	4	1	19
Hudson et al. (2005)	8	6	4	3	21
Hudson et al. (2008)	9	5	3	1	18
Hudson et al. (2009)	9	5	3	2	19
Hudson et al. (2009b)	10	5	3	2	20
Hudson et al. (2012)	9	4	4	0	17
Kilbourn et al. (2011)	8	2	3	0	13
Walsh & Schmidt (2003)	6	4	2	0	12
Walsh et al. (2007)	9	5	5	4	23
Behavioural interventions					
Carter (2006)	9	2	4	3	18
Keefe et al. (2005)	9	3	5	4	21

Table 6 continued

Study	Reporting (total = 11)	External validity (total=11)	Internal reliability (total= 5)	Internal validity - confounding (total=5)	TOTAL SCORE (total=32)
Meaning/bereavement based interventions					
Allen et al. (2008)	10	2	4	2	18
Duggleby et al. (2007)	11	4	2	0	17
Kissane et al. (2006)	8	4	5	4	21
Kwak et al. (2007)	9	4	3	0	16
MEAN SCORE (RANGE)	9.0 (6-11)	4.0 (2-6)	4.3 (3-5)	1.9 (0-5)	18.8 (12-23)

Overall, the quality of reporting was high. The most common weaknesses of studies were not providing full details of potential confounders and not describing the characteristics of participants lost to follow-up. In addition, very few studies included any measurement of clinical – as opposed to statistical – significance, making it difficult to ascertain the extent to which observed changes in outcome measures were meaningful for the participants who took part. Few studies included any discussion of effect size.

External validity scores were generally relatively low, despite the fact that all of the studies were carried out in hospice or other medical settings. In almost all cases sampling was opportunistic rather than random. This, combined with high rates of refusal and attrition, meant that samples were frequently biased in their makeup. The demographics of participants were overwhelmingly skewed towards female Caucasians. None of the interventions was provided as part of routine care, meaning that participants were referred specifically for entry into a study as opposed to a standardly provided service. In the majority of studies, however, the interventions were delivered by qualified professionals with regular caseloads. The Cahill et al. checklist also includes an item for rating whether therapists were free to use a “wide variety of procedures”. Only one study (Walsh et al., 2007) scored positively for this item; in other cases the interventions were clearly circumscribed and/or manualised. Arguably, however, therapist freedom may be less relevant to this set of studies where interventions targeted a very specific population; indeed, 19 out of 23 studies did not include descriptions of participants’ “presenting problems”.

Internal reliability assesses the risk of bias in the delivery and measurement of interventions and their outcomes. All of the studies used outcome measures with established psychometric properties. In most cases the statistical analyses were

appropriate but in two studies multiple comparisons were carried out without appropriate adjustment (Allen et al., 2008; Carter, 2006), and three studies with very small samples did not conduct statistical analyses at all (Duggleby et al., 2007; Kilbourn et al., 2011; Walsh & Schmidt, 2003). Eleven studies employed some form of fidelity check on adherence to the intervention.

Internal validity – confounding assesses the risk of selection bias and confounding factors. The high degree of variability in this domain was due to the difference between RCTs and uncontrolled trials. The nature of nonrandomised and uncontrolled trials designs renders them susceptible to selection bias, making it difficult to ascribe any changes measured to the intervention itself. This limits what can be said about the efficacy of the intervention beyond standard care. In many of the studies high rates of attrition were also a problem, both reducing the sample size and biasing its composition. Only half of the studies adequately controlled for drop-outs in their analyses (e.g. by using intention-to-treat criteria) and only seven carried out a power analysis. Among uncontrolled trials there was also little investigation of potential confounding variables, such as the nature and degree of participants' caregiving responsibilities and any other support they were receiving. However, there were also several examples of rigorously conducted trials involving independent data-collectors and analyses which controlled for confounders and missing data.

Problem-solving interventions

Problem-solving interventions were evaluated by six of the 23 studies (Cameron, Shin, Williams, & Stewart, 2004; Demirir et al., 2010; Demirir, Oliver, Wittenberg-Lyles, & Washington, 2011; Demirir et al., 2012; McMillan et al., 2006; Meyers et al., 2011). These interventions aimed to help caregivers learn generalisable

mental strategies for approaching unforeseen challenges. Problem-solving training can be thought to serve a twofold purpose, both helping people to generate solutions to the problems they face and improving their confidence in doing so (Houts, Nezu, Nezu & Bucher, 1996).

All six studies drew on one (or both) of two problem-solving intervention models: the COPE model (Houts et al., 1996) and the ADAPT model (D’Zurilla & Nezu, 2007). Both are based on the cognitive-behavioural framework developed by D’Zurilla and colleagues (e.g. D’Zurilla, 1986; D’Zurilla, Nezu & Maydeu-Olivares, 2002). Within this model, a number of “problem-solving styles” and “problem orientations” are distinguished by factors including a person’s motivational attitude, their appraisal of their coping resources and their ability to generate solutions. The model is grounded in a large body of research and problem solving training has been applied in the treatment of various psychological difficulties (e.g. D’Zurilla & Nezu, 2010).

Of the six studies, three were RCTs and three had single group designs. All found some support for their interventions. The most robust evidence comes from the RCTs by Meyers et al. (2011) and McMillan et al. (2006). Meyers et al. recruited a large sample across five sites and obtained follow-up data at six months. Findings showed that caregivers in both intervention and control groups underwent deterioration in their quality of life, but for those who received problem solving training the rate of deterioration was lower. Meyers et al. (2011) were rare among authors in their consideration of clinical significance; however, their method of measuring it based on effect size is somewhat obscure and unfortunately the authors do not report cell means, standard deviations or numbers-needed-to-treat. Interestingly, in this study there were no significant differences between the two

groups in problem-solving skills at follow-up. This finding is mirrored in the studies by Cameron et al. (2004), Demirir et al. (2011) and McMillan et al. (2006). Although it is not possible to draw conclusions about mediating variables on the basis of cell means alone, it raises the possibility that changes in quality of life may not be attributable to changes in problem-solving skills. Alternatively, it may be that the measures used were unable to detect changes in problem-solving skills.

McMillan et al. (2006) also found that caregivers of patients receiving hospice care benefited from their COPE intervention, with scores on a quality of life measure improving by 10% and symptom burden declining by 30% at two-week follow up. These findings are bolstered by the inclusion of a control arm of participants who received an equal number of non-problem-solving supportive visits and who did not show the same improvements.

The three studies employing a single-group design (Cameron et al., 2004; Demirir et al., 2010, 2011) also found some evidence for positive changes following their problem-solving interventions, including decreased anxiety and approach-avoidance conflict. Mindful of potential resource constraints in palliative care settings, Demirir et al. (2011; 2012) investigated the feasibility of delivering problem-solving training via videophone. In their most recent study, participants were randomised to receive problem-solving training either face-to-face or via videophone. Participants in both trial arms showed reductions in anxiety and improvements in problem-solving skills, and there were no differences between the groups.

Psycho-educational/supportive interventions

Interventions were classified as psycho-educational/supportive where professionals provided information or guidance to caregivers. These interventions

varied in their breadth and structure but broadly speaking shared the common aim of empowering caregivers with knowledge and skills in order to help them deal with current difficulties and prepare for future challenges. Of the 23 interventions, 11 were primarily psycho-educational/supportive (Hannon, O'Reilly, Bennett, Breen, & Lawlor, 2012; Harding et al., 2004; Henriksson, Arestedt, Benzein, Ternstedt, & Andershed, 2012; Hudson, Aranda, & Hayman-White, 2005; Hudson et al., 2008; Hudson et al., 2009a; Hudson, Thomas, Quinn, & Aranda, 2009b; Hudson et al., 2012; Kilbourn et al., 2011; Walsh & Schmidt, 2003; Walsh et al., 2007).

A programme of research by Hudson and colleagues has seen the development, refinement and evaluation of various group and individual psycho-educational interventions. Hudson et al. draw on Lazarus and Folkman's (1984) "stress appraisal and coping model", which proposes that a person's ability to cope with stress is determined by their appraisal of the situation and their own coping resources. Like D'Zurilla's (1986) problem-solving model, it is based on cognitive-behavioural principles. In terms of its relationship to psycho-educational initiatives it acts more as a guiding framework rather than a specific model for intervention.

Two early studies by Harding et al. (2004) and Hudson et al. (2005) found limited support for psycho-educational interventions. Harding et al. (2004) failed to find any significant effects following a six-session group intervention, despite positive feedback from participants. As the authors propose, this may be due to high rates of attrition reducing the power of their analysis, and/or the use of "global" measures of distress and wellbeing (which might be insensitive to the kinds of changes which can be expected in this context). Hudson et al. (2005) carried out an RCT of a brief one-to-one educative intervention. Significant group differences were observed on a measure of "caregiver reward", but the absence of any effects for

caregiver preparedness, confidence and self-efficacy does call into question the success of the intervention in achieving its purported aims.

More encouraging findings come from three more recent studies of group psycho-educational programmes (Hudson et al., 2008; 2009a; Henriksson et al., 2012). In two uncontrolled trials, Hudson et al. (2008; 2009b) found that caregivers who attended their groups showed improvements in self-reported confidence and preparedness. Findings by Henriksson et al. (2012), who evaluated a similar group intervention using a quasi-experimental design, corroborate this picture. Henriksson et al. (2012) do not state how their control group was recruited and the non-randomised design renders the findings susceptible to selection bias; nevertheless, the study provides further evidence that a psycho-educational intervention can add to standard palliative care. Again, a further limitation common to all three studies is the absence of measurements of clinical significance. It is also worth pointing out that with the exception of the preparedness measure in Henriksson et al. (2012), effect sizes across these studies were generally small.

More recently, Hudson et al. (2012) found preliminary evidence for the merits of a single-session psycho-educational intervention. These findings are particularly noteworthy given that during the rapidly changing and highly uncertain period before a patient's death, one session may be all a caregiver is able or willing to attend. Two further studies looked at the benefits of one-off "family meetings" in hospice settings (Hannon et al., 2012; Hudson et al. 2009b). In these interventions, family members were given the opportunity to discuss issues pertaining to patient care in a structured meeting with healthcare professionals. Both studies found evidence for the effectiveness of such meetings in addressing family members' unmet needs. The longevity and psychological impact of these effects, however, remain unclear.

Two feasibility studies, both uncontrolled trials, evaluated telephone support interventions with a psycho-educational focus (Kilbourn et al., 2011; Walsh & Schmidt, 2003). These interventions shared a degree of overlap with those categorised as “bereavement/meaning-based” but their structured format, involving topics similar to those covered in the psycho-educational groups, made them more appropriately categorised here. Small sample sizes precluded analyses of outcome data but there were trends in both studies for decreased caregiver stress and depression.

Walsh et al. (2007) evaluated an intervention comprising six visits from a carer’s advisor who offered needs-based practical and emotional support, advice and information. Similar to the approach used in the family meetings described above, this intervention adopted an open-ended format, focusing primarily on caregivers’ current issues rather than relying on a structured protocol. Caregivers receiving the intervention were compared to a control group who received standard palliative care. In this study, no treatment effects were observed. Walsh et al. outline several possible reasons for this, leaning towards the idea that the intervention was too brief. Inspection of the data also shows there was a high degree of variability in psychological distress across the sample, which - along with higher than expected attrition rates - may have limited the power of the study to detect differences between the groups. Also interesting are the trends observed across the sample as a whole. As in Meyers et al.’s (2011) study, quality of life generally deteriorated, but psychological distress and caregiver strain decreased. It is possible that there was an ameliorative effect of the palliative care services from which participants were recruited, and the open-ended format of this intervention may not have been sufficiently different from standard care to effect changes on the measures used.

Behavioural interventions

Two studies, both RCTs, looked at interventions employing a primarily behavioural approach (Carter, 2006; Keefe et al., 2005). These interventions bore similarities to those in the above categories but were unique in that each targeted specific problems experienced by caregivers using tailored behavioural programmes. Carter (2006) evaluated an intervention designed to improve participants' sleep, derived from empirically-grounded treatments for insomnia. Those who received the intervention were compared to a control group who received training on back health. Improvements in quality of life and sleep were seen in both groups and there was some evidence for superior improvement at certain time-points in the intervention group. The findings are limited, however, by the use of unadjusted multiple comparisons in the analysis, which inflates the risk of Type I error.

More convincing evidence comes from the study by Keefe et al. (2005), who evaluated a three-session pain management programme for patient-caregiver dyads. Caregivers who received the intervention reported significantly higher self-efficacy for managing patients' pain and other symptoms. The authors adjusted for unequal baseline levels of self-efficacy in their analysis and obtained relatively large effect sizes on these two outcome measures. There was a non-significant trend for decreased caregiver strain in the intervention group but there were no discernible effects on mood. These findings lend preliminary support to the value of short term pain-management training, although the extent to which these benefits translate into more generalised improvements in caregiver wellbeing is unclear.

Bereavement/meaning-based interventions

Four studies evaluated bereavement/meaning-based interventions (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008; Duggleby, Wright, Williams, Degner,

Cammer & Holstender, 2007; Kissane et al., 2006; Kwak, Salmon, Acquaviva, Brandt, & Egan, 2007). These interventions focused less on the daily practical and emotional strains of caring and more on the meaning for caregivers of being in this role and facing the approaching death of their family member.

The uncontrolled trial by Kwak et al. (2007) is impressive on account of its large sample size (926) and the flexibility of the intervention, which could be altered in terms of its length and delivery format. This study evaluated a “train the trainers” initiative, whereby professionals and leaders from a range of organisations attended a five-day course to learn the intervention model. The programme was based on the “Hospice Experience Model of Care” developed by Egan and Labyak (2001), which focuses on the existential impact of facing the death of a loved one and seeks to help caregivers achieve a sense of “closure”. Unlike cognitive-behavioural models, which focus more on alleviating distress, the model embraces the idea that the end of life period has the potential to stimulate positive growth.

Kwak et al. (2007) obtained promising results, especially on a measure of “comfort with caregiving”. However, these findings were based on only the 48% of participants who completed both baseline and follow-up surveys. It is likely they were skewed upwards by self-selection of participants who derived benefit from the programmes. The design of the study also precluded any kind of fidelity check and, as the authors note, it is probable that the interventions delivered were quite variable.

Two studies used a writing-based intervention (Allen et al., 2008; Duggleby et al., 2007). Allen et al. (2008) evaluated a novel intervention in which caregivers and patients constructed a “legacy scrapbook”; a personal and meaningful record of significant life experiences, achievements and memories. The theoretical basis of the intervention is somewhat loosely defined and the authors draw on aspects of multiple

models including Life Review, Dignity Therapy and CBT. As in Kwak et al.'s study, the aim was to enhance the positive meaning of caregiving. In this RCT, there appeared to be a buffering effect of the intervention on caregiver stress. This finding is confounded, however, by the disparately higher levels of distress and depression at baseline in the intervention group. Duggleby et al.'s (2007) single-group feasibility study involved a journal-writing intervention designed to inspire and maintain hope in caregivers. The small sample size precluded statistical analysis, meaning that the positive findings can only be viewed as preliminary. The theoretical basis of the intervention also needs establishing on firmer ground – it is not clear what the justification is for placing hope centre stage.

Kissane et al. (2006) evaluated an intervention designed to prevent the development of complicated grief in bereaved relatives. The study has several strengths, including the inclusion of a control group, the long follow-up period (13 months) and the use of measures of family functioning in order to distinguish sub-groups within the sample. Findings provided only limited support for the intervention, with only the most distressed families showing significant changes in distress and depression, and some families (those classified as “hostile”) appearing to fare worse than controls. These findings are difficult to interpret, however, as they are based on small sub-groups of the sample, and the equivalence of the comparison groups is not clear.

Discussion

Summary of main findings

The 23 studies in this review evaluated a range of interventions, most of which were based on well-defined, manualised protocols and rooted in theory or prior research. Interventions were classed into four types based on their aims and

theoretical approaches: problem-solving, psycho-educational/supportive, behavioural and bereavement/meaning-based. The most common format was individual face-to-face but other formats included carer groups, carer-patient dyads and telephone-delivered. The majority of interventions comprised one to three sessions. Strengths of the study set as a whole included generally high standards of reporting, the use of established psychometric measures and the fact that all interventions were carried out in clinical settings.

Overall, the studies provide promising evidence for the effectiveness of psychological interventions for caregivers of patients at the end of life. Seventeen studies found statistically significant improvements following their intervention and in the remaining six, five of which lacked statistical power, the trends were in expected directions. Outcomes in which positive changes were seen included: quality of life, preparedness, benefits of caregiving and self-efficacy. Only one study found evidence of a negative effect, and this was for a small sub-group of participants.

These findings are tempered, however, by the limitations of the study-set. Conducting research in the field of end-of-life care is notoriously difficult (Hudson, Zordan, & Trauer, 2011) and many of the studies suffered from methodological shortcomings. Across the study set, low uptake rates and high rates of attrition limited the power of analyses and biased the composition of samples. Small sample sizes rendered effect sizes unreliable and several studies did not report sufficient data to enable their calculation. For those which did, effect sizes were, on the whole, modest, and the absence of considerations of clinical significance makes it difficult to determine the distribution and extent of observed changes among participants.

Of the four classes of interventions, the strongest evidence is for problem-solving interventions. Two well-designed RCTs found that as little as three hours of

problem-solving training can help improve caregivers' quality of life. These studies scored highly on the *internal validity* domain of the Cahill et al. (2010) quality checklist, reflecting the robust design of the trials. Problem-solving interventions are grounded in a well-established theoretical and research tradition and the consistency of approaches across the studies lends further weight to their reliability. There is also emerging evidence that this kind of intervention can be delivered remotely via video-phone.

Psycho-educational/supportive interventions also show promise and the evidence suggests that a group format may be particularly effective. Structured family meetings also appear to be an effective way of eliciting and addressing caregivers' current concerns. Studies in this category generally scored well on the *internal reliability* domain of the Cahill et al. checklist, employing appropriate methods to monitor the interventions and measure their outcomes. They fell down on the *confounding* domain, largely due to the predominance of uncontrolled trials. The programmes developed by Hudson and colleagues are the product of many years' clinical and research experience. The cumulative nature of their research and its incorporation of service user feedback lend the interventions face validity in the absence of an established theoretical model. Again, the data suggest that brief interventions of one to three sessions can result in measurable changes on caregiver competence, preparedness and rewards. Randomised controlled trials are needed to establish the efficacy of these interventions beyond standard palliative care.

Four studies provide tentative evidence for the benefits of bereavement/meaning-based interventions. These interventions took a more long-term perspective, considering the implications of the pre-death period for a person's subsequent adjustment and emotional wellbeing. They focused on the significance

for caregivers of their unique experiences and aimed to enhance positive meaning-making and personal growth. The four studies falling in this category were more varied and drew on a range of theoretical approaches; there was little in the way of a progressive research programme. Most were limited by small sample sizes and other methodological flaws, but overall they provide tentative evidence for the merits of this approach.

Unlike those in the other categories, the two behavioural interventions were both designed to target particular challenges experienced by caregivers: sleep difficulties and patient pain-management. The positive findings in both studies were limited to specific outcome measures, and on their own they provide only preliminary support for the benefits of these interventions.

Methodological considerations

One of the difficulties in drawing conclusions from the studies in this review is the incomparability of different service contexts and the heterogeneity of individual caregiving trajectories. Participants in these studies were frequently receiving other, diverse forms of support in addition to the evaluated interventions. This makes it difficult to establish whether benefits observed in one context translate into ubiquitous benefits of the intervention or are characteristic of its fit within the service. It also makes it difficult to interpret the findings from uncontrolled trials, where the “normal” trajectory is unclear or, indeed, non-existent.

Studies used a broad range of outcome measures, from the general (e.g. quality of life) to the specific (e.g. self-efficacy for managing pain). Arguably, in the rapidly changing and emotionally charged context of end-of-life care, factors external to the intervention might be thought to play a major role in influencing psychological wellbeing. It is to their credit then that studies were able to

demonstrate measurable outcomes following the interventions. Some studies used outcomes measures linked to the aims of their interventions, such as preparedness or “sense of closure”. More specific outcome measures such as these may be at risk of demand characteristics as the link to the intervention is more obvious. On the other hand, changes on such measures may be more reliably attributed to the interventions, and may capture more realistically the outcomes achievable in this context.

Several studies elicited written or verbal feedback from participants about their experiences of the intervention. Almost unanimously, participants gave favourable qualitative feedback. In some cases (e.g. Harding et al., 2004; Walsh et al. 2007) the positive qualitative data was not mirrored in the quantitative data. Again, it is possible that qualitative surveys are more subject to demand characteristics than quantitative rating scales, as participants are often commenting on how they found the intervention itself rather than their current psychological state. It is also possible that some of the effects of the interventions were not captured in quantitative outcome measures, which may have been more influenced by extrinsic factors such as the patients’ health. The finding that in some cases problem-solving interventions appeared to improve quality of life without necessarily improving problem-solving skills or confidence suggests that quantitative outcome measures may be insufficient to capture the mutative factors of an intervention at any given time.

Limitations of the review

This review focused specifically on psychological interventions; “alternative” therapeutic approaches and practical/social support-based interventions were excluded. The focus was also limited to the period shortly before the patient’s death – i.e. palliative care. There is considerable research focusing on the earlier stages of caregiving, and a recent meta-analysis concluded that there is good evidence for

supportive interventions during this period (Northouse, Katapodi, Song, Zhang, & Mood, 2010). Clearly this literature is also relevant to the one reviewed here. It is possible, for instance, that behavioural interventions, which were relatively under-represented in this review, may be more appropriate to the earlier stages of caregiving, when relatives are perhaps more likely to be learning new skills such as patient symptom-management.

The quality checklist used in this review also has its limitations. Its utility lies in its capacity to illuminate the strengths and weaknesses of individual studies and groups of studies. It does not, however, provide a means of quantifying the strength of the evidence, and individual figures cannot be used as yardsticks by which to draw comparisons. Due to the unequal distribution of items across the four domains, it is not the case, for example, that a study with a higher overall score is necessarily superior to one with a lower score (e.g. it may score high on reporting but low on internal validity). A further limitation lies in the fact that studies were not independently rated by another researcher, which would have lent reliability to the scores and minimised bias in the evaluation of studies.

Research implications

Future research could explore which types of approaches are best suited to different clinical contexts and caregiver populations. It is likely that caregivers' psychological states fluctuate a great deal at this time, and follow highly variable trajectories. For example, some people may begin to feel relief when the person they are caring for nears death; for others this may be the final dawning of realisation and a time of acute distress. Of the studies reviewed, only two selected participants with specific presenting problems (Kissane et al., 2006; Carter, 2006), and a further one study (Walsh et al., 2007) targeted caregivers with high levels of psychological

morbidity. The study by Kissane et al. (2006) highlights the fact that one size does not fit all and the need for researchers to be attuned to individual variation. Optimal routes of access (e.g. self-referral vs. active outreach) and the impact of offering people a choice of intervention are other unexplored areas.

Further research is also needed into the long-term effects of interventions. With regards to bereavement interventions, the evidence suggests that only those at risk of complicated grief benefit from therapy (Schut & Stroebe, 2010). At this stage, it is not clear whether and to what extent intervening earlier, during palliative care, can also help to prevent complicated grief.

More research is needed into behavioural interventions and those adopting a bereavement/meaning-based approach. It is notable that the studies in these categories were of a more piecemeal fashion, tending not to build on the findings of one another. Considering their theoretical underpinnings, the bereavement/meaning-based interventions in particular were based on a diverse range of models and theories. Schut and Stroebe (2010) point out that research in the fields of palliative care and bereavement has historically been kept quite separate. Building bridges between these two literatures could be mutually beneficial.

Other models and therapeutic approaches – which often have a lot to say about the end-of-life period – have been relatively neglected in carer research: for example, narrative and dignity therapy (e.g. McClement et al., 2007; Noble & Jones, 2005; Romanoff & Thompson, 2006) and existential therapy (e.g. Breitbart, Gibson, Poppito & Berg, 2004; Downey, Curtis, Lafferty, Herting, & Engelberg, 2010). Future research should look at ways in which family members can be included in such interventions, which have tended to focus on the patient. In fact, it is notable that few studies involved carer-patient dyads and even fewer involved the family as a

whole. Research by Kissane and colleagues suggests that family dynamics play an important role in adjustment to bereavement (Kissane et al., 1996) and future research might usefully explore ways in which interventions can involve people's wider systems for the mutual benefit of patients and relatives.

From a methodological standpoint, future research should take into consideration the likely impact of attrition in sampling and analyses. Kirchhoff and Kehl (2008) offer guidance for researchers in the field of palliative care on methods for improving recruitment. In addition, efforts should be made to recruit a more diverse range of participants, including men and those from black and minority and ethnic groups. The latter are known to be under-represented in hospices (Help The Hospices, 2012) and in research in the field more generally (Hudson et al., 2011).

Researchers should also include measures of clinical as well as statistical significance in their analyses. Finally, alternatives to the large-scale randomised control trial might also be fruitfully explored. Given the importance of the service context, there may be a place for practice-based evidence generated from local-level initiatives with data collected as part of routine care.

Theoretical and clinical implications

Critics of the “medicalisation” of healthcare argue that end-of-life care focuses too much on the physical aspects of disease and body mechanics and that death is too often seen as a medical failure (e.g. Farber et al., 2003; Milberg & Strang, 2007). The studies reviewed here see a role for professionals in moving beyond symptom management and embracing the psychological, emotional and spiritual aspects of caregivers' experiences. They provide promising evidence that psychological interventions can be of benefit to caregivers in palliative care.

The ethos of providing psychological and emotional support is very much embedded in the hospice movement itself, which espouses a model of holistic, person-centred care. In practice, hospice staff may well be delivering psychological “interventions” as part of day-to-day practice; not in the form of manualised therapies, but as bedside conversations or telephone check-ups. In fact, it seems intuitively likely that almost any form of care provided in this context will involve some form of emotional support. The controlled trials in this review suggest there is scope for more “formal” psychological interventions, rooted in theory and empirically tested, to add to multi-disciplinary hospice care and to improve caregivers’ wellbeing. What is more, they suggest that such interventions need not involve extensive resources and can be delivered in a few sessions by members of a multi-disciplinary team.

Given the low uptake rates in these studies, those designing interventions would do well to consider the frequent ambivalence of carers about accessing support for themselves. There is a need to be pragmatic about the length and format of interventions. It is also perhaps useful to bear in mind that not everyone will benefit from a psychological intervention at a given time, and for some caregivers, well-placed, “informal” conversations may be extremely important. It is possible that some of the techniques and ideas included in the formal interventions evaluated here might also be applicable in a less formal way to those who are unable or unwilling to attend regular sessions.

As the evidence-base expands, policy guidelines are needed to aid its implementation in practice. Work should be done to consider the ways in which findings from interventions studies can inform local and national policy guidelines, as well as remaining flexible enough to be implemented in practice.

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Part 2: Empirical Paper

Caring at home for a family member with a terminal illness: a qualitative study of relatives' experiences

Abstract

Objective: Relatives looking after a terminally ill family member at home often face numerous challenges. Studies into relatives' experiences of home caregiving have been criticised for their descriptive nature and lack of theoretical underpinnings. This qualitative study explored the emotional challenges faced by home caregivers, and their experiences of professional services, from the perspective of existential psychology.

Method: Semi-structured interviews were conducted with 15 recently bereaved relatives who had cared at home for a family member with cancer. Transcripts were analysed using the Framework approach in order to identify themes within the data.

Results: Participants' experiences of being a caregiver and of professional support were highly varied. The analysis generated 14 themes which were organised into a framework based on Yalom's (1980) four "existential conditions": responsibility (e.g. "being the linchpin of care"; "you only have one chance to get it right"), isolation (e.g. "being on my own", "being held in mind"), death (e.g. "knowing but not knowing") and meaningfulness (e.g. "finding meaning and solace in caring"). Professionals were perceived as influential in both helping and, sometimes, hindering participants in meeting the challenges they faced.

Conclusions: Relatives caring for a terminally ill family member at home face complex emotional challenges in navigating the caring role and coming to terms with the approaching death. Professionals have an important role to play in helping them deal with these challenges. Existential psychology provides a framework which may usefully aid clinical practice and inform future research.

Introduction

Most people in the UK would prefer to die in their own homes (Department of Health, 2012a) and increasing the proportion of home-deaths is now a key aim of national policy (Department of Health, 2010; Exley & Allen, 2007). As the population ages, and more people are being cared for in the community, relatives and other informal caregivers are playing an increasingly important role in looking after those with a terminal illness.

Relatives of terminally ill patients may face numerous challenges in their caregiving role. Often, they take on high levels of responsibility, and are at increased risk of poor physical and mental health or even burnout (Linderholm & Friedrichsen, 2010; Proot et al., 2003; Wennman-Larsen & Tishelman, 2002). As they look ahead to the death of their family member and their own lives afterwards, they may experience in advance a sense of loss or “anticipatory grief” (Clukey, 2008; Grassi, 2007; Johansson & Grimby, 2012). Feelings of inadequacy (Brobäck & Berterö, 2003), helplessness (Linderholm & Friedrichsen, 2010; Milberg, Strang & Jakobsson, 2004), confusion (Milberg & Strang, 2007) and fear (Phillips & Reed, 2009) are common.

As the domestic environment becomes the context for medical interventions and the physical realities of illness, caregivers may find themselves navigating complex and uncertain roles (Carlander, Sahlberg-Blom, Hellström, & Ternstedt, 2011). Communication within the wider family may be difficult and it should not be assumed that the family network is always a source of mutual support (Kissane et al., 1996; Kissane et al., 2006). It has been argued that the idealisation of home-based,

“collaborative” care downplays the complex practical, social and emotional challenges faced by home caregivers (Exley & Allen, 2007).

The position of professionals in this context, how they are perceived and how they can help or hinder relatives in their caregiving role, is a complex matter. In the UK, end-of-life or “palliative” care is provided by a number of services including local NHS primary care trusts, hospitals, hospices and other voluntary sector organisations. Palliative care services have an important role to play in supporting families, as well as patients themselves (Department of Health, 2008; Teno, Casey, Welch, & Edgman-Levitan, 2001). The “hospice model” of specialist, holistic palliative care is well supported by research and has been upheld as a model of excellence which other medical services should aspire to replicate (Ellershaw & Ward, 2003; Higginson & Evans, 2010).

Several studies have looked at the ways in which professionals can support relatives during end-of-life care. Factors such as good patient symptom-management, involving relatives in decision-making, consistent communication and reliability of support are frequently identified as important (e.g. Andershed, 2006; Milberg et al., 2004; Munck et al., 2008; Proot et al., 2003). Funk, Allan and Stajduhar (2009) describe the significance for caregivers of having a trusting relationship with healthcare professionals and the sense of security that comes with feeling well-supported. Hebert and colleagues describe the varied ways in which conversations with professionals can help relatives to feel more prepared (Hebert, Dang, & Schulz, 2006; Hebert, Schulz, Copeland, & Arnold, 2009; Hebert, Schulz, Copeland, & Arnold, 2008). In contrast, conflicting information, discrepancies between decisions and interventions, and unexpected occurrences can cause confusion and distress

(Milberg et al., 2011; Neuenschwander, Bruera, & Cavalli, 1997; Radwany et al., 2009).

Despite the advances made by the hospice movement, and the research on carers' needs, provision of support for carers has been identified as an under-acknowledged priority (Hudson & Payne, 2011). A recent government report suggests that only 50% of family carers get as much support as they want from health and social services during the last three months of their loved one's life, and only 59% feel adequately supported at the time of the death (Department of Health, 2012b). Barriers to effective care include taboos around talking about death and dying (Dying Matters, 2011), reluctance amongst relatives to voice their personal needs (Funk et al. 2010), lack of trust in health professionals (Andershed, 2006), poorly resourced services (Hudson & Payne, 2011), and the psychological impact (for both clients and professionals) of being in a highly emotional and uncertain situation (de Haes & Teunissen, 2005; Hebert et al., 2008).

The literature on relatives' experiences and needs during end-of-life care contains a large proportion of qualitative studies (Andershed, 2006). These studies have been criticised, however, for their tendency to report findings as broad-brush descriptive lists and to ignore individual variability (Downey et al., 2010; Funk et al., 2010). Qualitative studies in the field generally make little use of theory in analysing and interpreting data, nor do they typically seek to develop new theory based on their findings (Funk et al., 2010). This is particularly the case for studies evaluating the support provided by professionals, which often focus narrowly on caregiver satisfaction (Funk et al., 2010; Stajduhar et al., 2011).

Existential issues in end-of-life care

As well as facing the loss of a loved one, family caregivers may be threatened with the loss of important goals, values and roles, and deep-rooted beliefs and implicit assumptions about justice, fairness and predictability (Park & Folkman, 1997). Yalom (1980) writes about a confrontation with death as a “boundary situation” or “awakening experience”; that is, an experience which jolts us from day-to-day life and acquaints us with the stark realities of human existence. For some, this can be a time of existential suffering, in which the transience of life is brought forcefully into awareness.

Despite its potential relevance to palliative care, existentialism as a theoretical perspective has been relatively absent within the literature (Downey et al., 2010; Milberg & Strang, 2007). Originating in philosophy, the term “existentialism” is broad in its scope and tends to be used somewhat loosely, making it difficult to define concisely. Within the fields of psychology and psychotherapy, existentialism is essentially concerned with the experiential conditions of human existence. Synthesising the work of a host of existential writers, Yalom (1980) outlines four “existential givens” of existence: freedom (and its corollary, responsibility); isolation; meaninglessness (and the need to find meaning in life); and death. According to Yalom, these are fundamental features of existence which both haunt us and propel us in our life endeavours. The anxieties provoked by our (sometimes unconscious) awareness of these conditions, and our attempts to manage or avoid them, are thought to contribute to psychological and relationship difficulties. Existential therapists maintain that unearthing and confronting these anxieties has the potential to be curative and even growth-enhancing.

A recent review by Melin-Johansson, Henoch, Strang and Browall (2012) examined the literature on “existential concerns” for the relatives of patients receiving palliative care. They concluded that despite evidence for the prominence of such concerns at this time, few studies have investigated these aspects of relatives’ experiences. Of the 17 studies included in the review, most did not focus specifically on existential issues but looked more broadly at relatives’ support needs. In one of the exceptions, Albinsson and Strang (2003) used Yalom’s framework in a qualitative analysis of existential concerns among relatives of dementia patients being cared for in nursing homes. Based on their findings, the authors emphasise the need for staff to attend to existential concerns such as loneliness and death anxiety, and the need for further research in other contexts. Another study by Milberg and Strang (2003) drew on the existential construct of “meaningfulness” to explore a specific aspect of relatives’ experiences during ongoing home care. The findings highlighted ways in which caregiving afforded positive meaningful experiences for relatives – something often neglected in the literature (Andershed, 2006; Wong & Ussher, 2009). None of the studies examined in detail at the various challenges faced by home caregivers, and their experiences of professional services, from the perspective of existential psychology. Due to the diversity of the studies in terms of their focus and setting, the review does not provide a clear picture of the existential issues faced by relatives in this context.

The current study

This study aimed to explore the emotional challenges faced by those caring for a terminally ill family member, and the ways in which healthcare professionals can help or hinder them in dealing with these challenges. Existential psychology was used as a framework for understanding relatives’ accounts. The use of established

theory in qualitative research can help to enrich the analysis and provide an organisational framework for the data (Sandelowski, 1993). An explicitly theoretical approach was taken in this study with the view that this would afford a deeper understanding of the challenges faced by relatives and the ways in which professionals can support them. As indicated above, existentialism is perhaps less a theoretical model than a broad area of enquiry, and existential concerns (or “anxieties”) are often construed widely to include any state wherein individuals become conscious of themselves and their position in life. This broadness was seen as an advantage for the current study, which sought to look at the various emotional challenges faced by relatives, rather than honing in on any pre-specified construct. At the same time, there have been more rigorous attempts to theorise existentialist principles in particular fields (including Yalom’s (1980) work in the field of psychotherapy) which, it was anticipated, would serve as a source of insight in the analysis and interpretation of the data.

A qualitative methodology was chosen as befitting an inductive, exploratory study with a focus on subjective experiences (Flick, 2009; Smith, 2009). Semi-structured interviews were used as a means of capturing the complexity and variability of participants’ internal experiences.

In this study, bereaved relatives were interviewed retrospectively about their experiences throughout the whole trajectory of caregiving. This provided an opportunity to explore their experiences of the final few days and weeks before their family member’s death, and the ways in which their experiences changed over time. Although retrospective interviews are subject to recall bias, a further advantage of this approach was that it allowed a period of time for relatives to gain some distance

from their experiences, which – given their emotionally charged nature – may have been more difficult to reflect on and articulate at the time (Hebert et al., 2009).

In summary, the study addressed the following questions:

1. What are the emotional challenges faced by relatives caring at home for a family member with a terminal illness?
2. How can healthcare professionals help or hinder relatives in dealing with the emotional challenges they face at this time?

Method

Setting

The study was carried out within the community palliative care service of an inner-city London hospice. The hospice provided inpatient and outpatient care for terminally ill patients and their families, and employed a range of professional staff including doctors, nurses, social workers and psychologists.

Ethical approval

Ethical approval for the study was obtained from the University College London Research Ethics Committee (see Appendix A) and locally from the hospice research and development department (see Appendix B).

Recruitment

Participant eligibility criteria were:

1. Bereaved family caregivers of cancer patients who received hospice home-care. Cancer patients were targeted because cancer deaths tend to

be more predictable, allowing time for home-based care to be put in place. There were no restrictions with regards to the family caregiver's relationship with the patient.

2. The patient's death occurred approximately three months prior to the time of the study. This time-duration, for which there is precedence in the literature, provided a balance between leaving time for the immediate emotional impact of the death to lessen, and ensuring memories were still sufficiently recent to enable recall (Milberg, Strang & Jakobsson, 2004).
3. Aged 21 years or more.
4. Able to speak fluent English.

Eligible participants were identified by members of the research team working at the hospice (a consultant in palliative medicine and two clinical psychologists). Consecutive patient series sampling was used, whereby all participants meeting inclusion criteria during the study period were invited to participate, in the order in which they became eligible and until sufficient numbers were recruited. This relatively unconstrained sampling method was used with a view to recruiting participants from a range of socio-demographic backgrounds and with varied experiences. Recruitment ceased when it was felt that a rich data-set had been obtained, capturing both common themes and some of the variability in relatives' experiences.

Eligible participants were contacted by a member of the research team and informed about the study. Those who expressed an interest in taking part were sent written information about the study detailing its nature and purpose as part of an independent research program, distinct from their care at the hospice. Interviews were arranged at participants' convenience and took place either at the hospice or at

participants' homes. Signed consent was obtained on the day of the interview (see Appendices C and D for copies of the participant information sheet and consent form.)

Characteristics of participants

Of the 25 eligible participants, 15 consented to take part in the study and 10 declined. The main reasons given for declining were not feeling emotionally ready to talk and not having time to attend an interview.

The characteristics of participants are shown in Table 1. Eleven women and four men participated. The mean age was 50 (range: 27-66). The majority (n=10) were White British, three were of Asian ethnicity, one was Black Caribbean and one was Black African. Ten participants were working at the time of the study and five were either retired or unemployed. Six participants had no educational qualifications, four had school-level qualifications (GCSEs or NVQs) and five had degrees or higher qualifications. Nine participants described themselves as Christian, four as Muslim and two as not following a religious faith. There were a range of patient-caregiver relationships, with the most common being mother – daughter/son.

Table 1: Characteristics of participants

Participant number	Gender	Age	Ethnicity (self-described)	Deceased family member
1	Female	55	White British	Mother
2	Female	49	White British	Uncle
3	Female	53	White British	Mother
4	Male	64	White British	Aunt
5	Female	60	White British	Partner
6	Female	62	White British	Brother
7	Female	30	Bangladeshi	Mother
8	Female	46	Black Caribbean	Husband
9	Female	53	White British	Sister
10	Female	46	White British	Mother
11	Male	66	White British	Wife
12	Female	27	Asian	Mother
13	Male	47	Black African	Mother
14	Male	38	Bangladeshi	Father-in-law
15	Female	57	White British	Mother

Interview

An interview schedule (see Appendix E) was developed based on the research questions and published guidelines on qualitative methodology (e.g. Smith, 1995; 2009). Interviews followed a semi-structured format, which allows the interviewer to remain flexible, using questions with discretion and responding to pertinent themes arising during the conversation. Interviews explored the whole caregiving trajectory, beginning with the time participants first found out their family member was unwell, moving on to the weeks and days before the death, and finally focusing on the death itself and its immediate aftermath. Participants were additionally asked about their experiences and conceptions of healthcare professionals/services and anything they would have liked to have been different about the care they received. Questions were designed to be minimally directive and were asked only when needed, so as to enable participants to tell their stories and to describe what was important to them. Follow-up probes were used to elicit details of participants' internal experiences such as their expectations, appraisals and emotions. At the end of the interview there was a debriefing period in which participants were given the opportunity to reflect on the process of talking and the feelings it brought up.

Analysis

The analysis was approached from a contextualist epistemological standpoint (Jaeger & Rosnow, 1988). Contextualism is an umbrella term for a host of theories which share the assumption that reality is not directly accessible but subjectively-constructed by active, interpreting minds. Contextualism does not deny the possibility of knowledge but emphasises the limits and context-dependency of human understanding. Multiple perspectives are valued in the interests not of absolute truth

but of “completeness” (Madill, Jordan, & Shirley, 2000), or what Stiles (1999) calls “permeability” - the capacity of a description or explanation to change understanding.

Interviews were audio-recorded and transcribed verbatim by the researcher. The data were analysed using the Framework approach (Ritchie, Spence & O’Connor, 2003), with the aid of NVivo qualitative data analysis software (QSR International). The Framework approach is a form of thematic analysis (Pistrang & Barker, 2012), widely used in applied policy research, involving the identification of recurring patterns, or themes, within the data. An advantage of this approach is its flexibility, being independent of any specific theoretical framework but adaptable to suit many (Pistrang & Barker, 2012). This allowed the analysis to be guided both by the data and by the theoretical framework. The Framework approach in particular provides a systematic process for developing a structural thematic map from a rich data set. The analysis was primarily an inductive process and during the early stages priority was given to the data itself. During the later stages, the theoretical framework was incorporated as an additional source of insight and as an organisational framework for the themes.

The analysis involved several stages. The first stage was a process of familiarisation, in which interview transcripts were closely read and discussed among the research team, and initial thoughts on pertinent themes were recorded. The second stage was a more rigorous process of “data management” which involved systematically working through the data set and indexing extracts to basic, low-level themes, or “codes”. At this stage, extracts were indexed inclusively and codes generated liberally, resulting in a list (or “index”) of around 80 codes. These were loosely grouped into thematic categories as the analysis proceeded. The third stage

was to synthesise these codes into a more meaningful framework. Initial index codes were scrutinised for their internal consistency and distinctness from one another, and collated or split where appropriate. Groups of codes were brought together to form higher-level themes. This was an iterative process whereby emerging themes were honed and refined with repeated checking of the raw data. At this stage, it was decided that Yalom's existential conditions provided a helpful way of organising the themes into four broad categories. The incorporation of this theoretical perspective also provided a further source of insight into the data and helped to enrich and develop the emerging themes. The final stage involved the distillation of data into (electronic) charts recording the material indexed under each theme for individual participants. This provided a further checking process as gaps in the charts were identified, and facilitated comparison across individuals and themes. (Appendix F shows examples of the stages of analysis).

In deciding on themes, attention was paid to the frequency of relevant material both across the data set and within individual transcripts. Thus, some of the themes were not universal but were highly prominent for a subset of individuals. The relative prominence of themes is indicated in the text of the Results section.

Credibility checks

Steps were taken to ensure the credibility of the analysis in accordance with published guidelines on qualitative research (e.g. Elliott et al., 1999; Parker, 2004; Stiles, 1999). A team-based approach was used to share ideas and guard against bias. Throughout data collection and prior to the main analysis, members of the research team independently read a selection of transcripts and generated thoughts on relevant themes. These ideas were used to inform the initial indexing of data. At the next

stage, prior to the synthesis of index themes, the research team met to discuss and agree on a preliminary template framework. In particular, the merits and cogency of using Yalom's four categories as a framework was discussed. Periodic updates on the developing thematic framework were then checked and discussed as the analysis proceeded.

Testimonial validity checks (e.g. Krefting, 1991) were also used, whereby summaries of the main themes in each interview were written and sent (individually) to participants, who were invited to provide feedback on their accuracy and comprehensiveness (see Appendix G). Summaries were sent to all but one participant (whom we were unable to contact at follow-up) and seven participants replied. Of these, six said they were entirely happy with the summary; one suggested minor amendments in emphasis.

Researcher perspective

The validity of qualitative analysis is enhanced by disclosure of the researcher's perspective (Caelli, Ray & Mill, 2003). I am a white male in my mid-twenties and carried out this research as part of a professional doctorate in clinical psychology. I have a background in philosophy and I am interested in existentialism and its relevance to clinical psychology. I have also had a personal experience of a close relative dying – not at home, but in a hospital – and some limited contact with palliative care professionals.

As described, the study took an explicitly theoretical approach, in the hope that this would make for a richer and deeper analysis. The particular approach adopted in this study was undoubtedly influenced by my own background and interests. Mindful of this, steps were taken to guard against the unwarranted

imposition of theory onto the data. From the outset, we did not tie ourselves to the theoretical framework and in fact a number of relevant theoretical approaches were considered. Throughout the research process, I endeavoured to reflect on and “bracket” my assumptions, aided by the team-based approach to data collection and analysis (Ahern, 1999; Fischer, 2009). Working within a contextualist epistemological framework, the aim in doing so was not to discount my own ideas, but to “shelve” them. Within this framework, there is acknowledgement that what the researcher brings to the process has the potential to afford interpretive insights (e.g. Fischer, 2009). Ultimately, the aim was not to elucidate universal truths but to provide one angle on participants’ narratives that carried meaning and plausibility. Bracketing was therefore seen as a means of ensuring that the research was not driven by idiosyncratic ideas, whilst allowing room for it to be informed by them.

Results

The analysis generated 14 themes which were organised into a framework based on Yalom’s four “existential conditions”: responsibility, isolation, death and meaningfulness (“meaninglessness” was re-classed here as “meaningfulness” as the latter better captured participants’ experiences). Although each of the themes captured a unique aspect of participants’ experiences, there was a degree of overlap between them, reflecting the interdependency of the four categories within Yalom’s framework. A summary of themes is shown in Table 2. Before the themes are presented, a brief contextual overview is provided in order to orient the reader to the data. Throughout this section and the next, participants are referred to as “relatives” and patients as “family members”. Participant numbers are given following quotations (e.g. P1) to denote speakers (see Table 1).

Overview and context

All 15 participants were involved, to varying degrees, in caring for their family member. Four lived with their family member throughout the duration of their illness, five stayed with them for a period of time, and six lived separately. All of the patients were cared for and eventually died at home but nearly all (13/15) also had periods of time as an inpatient either in a hospital or hospice. All received community-based medical and social care from a number of professionals including carers, district nurses, palliative care nurses, general practitioners and specialist doctors. The duration of patients' illnesses from diagnosis to death ranged from several months to five years, with the last few months usually being a period of rapid deterioration. Across the sample, experiences of being a caregiver and of professional support were varied. Six participants (P1, P4, P6, P8, P10, P13) had, on the whole, positive experiences of services, five had particularly negative experiences (P7, P9, P12, P14, P15) and the remaining four were more mixed (P2, P3, P5, P11).

Table 2: Summary of themes

Category	Themes
1. Responsibility	1.1: Being the linchpin 1.2: Constantly on the alert 1.3: “You only have one chance to get it right” 1.4: “Am I doing enough?”
2. Isolation	2.1: Being on my own 2.2: Being held in mind 2.3: Losing a relationship 2.4: Intimacy
3. Death	3.1: Knowing but not knowing 3.2: Repeated confrontations with mortality 3.3: Protecting family members from existential suffering 3.4: Thinking about mortality
4. Meaningfulness	4.1: Finding meaning and solace in caring 4.2: Acceptance and gratitude

Category 1: Responsibility

Participants frequently took on high levels of responsibility in their caring role and felt a strong imperative to do their utmost for their family member. The themes in this category concern relatives' experiences of managing the responsibilities of caregiving, and the role of professionals in helping them to do so.

1.1. Being the linchpin

As the people who knew them best and were with them most, relatives were at the centre of their family member's care. Whilst looking after them at home, relatives felt it was up to them to notice and respond to their family member's needs. This led to a feeling amongst some that their family member's wellbeing, and even their lives, depended on them:

But it was really crucial that I stuck around because without, you know, there were times when mum had a urine infection, something like that, and I know she would have died if I wasn't around, because, no disrespect to the carers, but they're not quite as involved as family are. (P10)

Although often unquestioningly adopted, this role was usually to some extent externally imposed – due, for example, to a lack of other support or the patient's reluctance to accept help from others. Caregiving often included medical responsibilities such as overseeing medication and relatives found themselves having to quickly learn new skills. Often, these responsibilities were welcomed, but some relatives felt unconfident at times with what they were asked to do.

Because you're not medical. And I know it's common sense, and most of it I kind of knew in a way, but I think it's just that you want that reassurance. (P15)

Relatives felt responsible for relaying information to professionals and ensuring their family members got the medical support they needed. Often it was up

to them to take the initiative in contacting professionals and several described periods of being constantly on the phone liaising with a network of agencies:

Because it seemed like if you wait - I don't think a day went past when I wasn't on the phone to someone or other about him. Always, always on the phone. (P2)

The five participants who had more negative experiences of services shouldered prolonged high levels of responsibility and described caregiving trajectories characterised by pressure, frustration and sometimes desperation. These participants particularly stressed the failures in coordination of care and found themselves constantly having to “fill the gaps” where communication failed:

There were too many agencies involved, too many numbers to remember, there were so many numbers....and agencies not collaborating with each other. That's the biggest thing, nobody's taking the coordination. (P14)

Individually, everyone who came to see my mum more or less were lovely, but there wasn't that coordination. And the thing is, the last thing as a member of the family we needed was to try and coordinate it ourselves. (P12)

By way of contrast, it was evident how much difference professionals could make by showing relatives that they were sharing the responsibility. Often, relatives needed someone to be proactive and to tell them they didn't need to be doing everything themselves.

But when [hospice nurse] came it was easier for me, because I used to just tell her and she used to say “just tell me, you don't have to go round making calls and all that, I'll do that for you, I'll contact them”, so that was really helpful. (P7)

For the six participants who had more positive experiences, there was a clear sense of shared responsibility with professionals and other carers. These participants described how the professional support network provided a sense of security, often underpinned by a timely and reliable “care package”.

And also what amazed me is that it happened so quickly and somebody came in, and it took a lot of pressure off us – not that we begrudged the time that we spent – but probably not really having any experience of that kind of care, I was just amazed at how good it was, how quickly it was arranged and how well it worked. (P4)

Participants particularly valued the availability of out-of-hours support.

Participant 1, for example, described an incident when she woke in the night to find her mother in an agitated state and the support she received over the telephone:

And they were brilliant. He said, “well I can get someone to come out and visit if you wish, if you need that?” I said “well I don’t think we need anyone but just to talk it through with you helps. She hasn’t got a temperature, she seems to be calming down now, drifting off again”. But it just scared me, it was just good to have that contact. Yeah it was really important. (P1)

1.2. Constantly on the alert

Given their responsibilities, relatives were often in a state of hypervigilance, constantly attuned to signs as to their family member’s condition.

And then you weren’t really sleeping because every few seconds you’re waking up and going “is she still breathing, is she still there?” and that kind of stuff, “why is she breathing like that, what’s wrong with her?” every 2 seconds, “mum are you OK?” (P12)

Even when they were not with them (and sometimes especially at these times), participants were thinking about their family member and many described a constant dread of something happening to them in their absence.

When I was at home I would go out, help out, come home, and it was always waiting for a phone call. Will I get that call today, you know? (P3)

Participants often put their family member’s needs above their own and described how difficult it was to think about themselves at this time. Several people mentioned neglecting themselves.

I was also told to look after myself as well, because I was doing so much for him. But you can't do for yourself because your mind is 24 hours a day on something else. (P2)

Particularly for those who lived with their family member, there was a sense that caring became an all-consuming job, around which their lives revolved. This could give rise to a surreal quality to life, in which familiar routines disappeared and the patient became the constant focus of attention.

P I wouldn't leave him. And I think, I was so wrapped up with him. I lost my purse 5 times.

I Did you? So it was hard to contemplate doing something for yourself?

P It was very very hard to... think of anything else. (P5)

It could also be physically and emotionally exhausting (although notably this was not often talked about).

As far as I know I was just the same as how I was before. I mean through [uncle]'s illness people kept telling me I looked ill. I looked ill and I looked tired. So, that's just one of those things isn't it, when you're caring for somebody else. (P2)

1.3. "You only have one chance to get it right"

In addition to attending to the patient's physical care, there was a common sense amongst participants of needing to ensure the death happened in the right way. Often, this meant enabling their family member's wish to die at home. It could also mean other things, such as ensuring the right people were present, respecting family members' religious beliefs and honouring their relationships.

And therefore, we have decided that when the time comes, she will be in her bed and we will be at her side. Which, you know, has happened, and until the last minute we were at the side of our mum. (P13)

Participants conveyed the sense of immediacy and momentousness that pervaded this time, such that attending to these things became a priority against which everything else faded.

Because at the time you go through it, you just think, right I'm going to do 110% because if I don't do this right, this is it, you know, I can recover, I've got the rest of my life to recover, she doesn't. (P12)

“Getting it right” could be a rather nebulous responsibility and a source of anxiety. This was particularly the case when participants felt that their ability to do so was compromised by factors beyond their control such as financial restrictions, lack of professional support and their family member’s physical or mental condition.

Because it's horrible if you're constrained, so that the last time in their life you can't do things just purely because of money, you know. (P10)

Several participants spoke about their position of knowing the patient better than professionals, and the responsibility they felt to advocate for their needs. In most cases, their views chimed with professionals’. In a few instances, however, relatives felt at odds with professionals, who were experienced as not taking into consideration their concerns and the patient’s needs.

I appreciate that we're not medical, but, sometimes when you're with another person all the time you do start to know, you know, what's better for them. And another medication wasn't going to be a good idea. (P9)

1.4. “Am I doing enough?”

Managing high levels of responsibility brought with it self-questioning and sometimes even guilt. This came up in almost all interviews and ranged from transient self-doubt to agonising states of self-accusation. Two participants in particular described repeatedly questioning whether they were doing the right things.

Participant 7 was constantly afraid of missing something that might help to forestall her mother's deterioration.

I was at home, and my brother and sister they used to visit once in a while when they were able to. So they used to pick up on things I didn't notice and I used to feel really guilty about that. I used to think "oh why didn't I think of that, why didn't I ask the doctor that?" (P7)

She further described the challenge of "juggling" conflicting thoughts and values.

And constantly I used to think "am I doing it right?" in the faith way, because you can't think – because in our faith it's whenever God decides – we can't think just because the doctor has said two weeks we can't think like that. (P7)

Participant 12 spoke about wrestling with the decision of how much to encourage her mother to eat in order to prolong her life. Even her thoughts and feelings at this time were subject to scrutiny.

Because at that time, you're going through such a range of emotions, and you think: you're a bad person for thinking "oh my God this is really hard, this is really difficult", you think "am I doing enough?" (P12)

Several others also criticised themselves for having "selfish" or negative thoughts, or for taking time off from being with their family member. Participant 8 described an incident when she left her husband in the hospice for one morning, returning to find his condition had worsened and blaming herself because he would not accept food or medication from others:

I said "it's my fault". And she [hospice nurse] said "don't blame yourself". I said "no it's my fault". She said "why?" I said "because I wasn't here". (P8)

A few participants spoke about the dilemma of when to ask for more help and the weight of these decisions when so much was at stake. Professionals could make a big difference in reassuring relatives:

...for me I always would think “I’m not doing it right”. And then [hospice nurse] was there to say “you’re doing everything right”, kind of thing. (P7)

Many participants said that it was important and comforting for them to know that they did all they could have done for their family members.

I can only survive by thinking that, you know, we did the very best that we could for him and that he went peacefully. (P6)

A few, however, voiced lingering retrospective doubts about whether they “*could have done more*”. In two cases, both of these thoughts (of having and not having done enough) were expressed within the same interview.

Category 2: Isolation

This category concerns participants’ experiences of their relationships with the patient, with friends and other family members, and with healthcare professionals. Themes illustrate the ways in which caregiving was experienced as a time of both isolation and connectedness with others.

2.1. Being on my own

Although most participants felt well-supported overall, most had at least one experience of feeling let down by services. Often this was due to failures in the coordination of care, resulting in scenarios such as patients being taken to hospital only to find that they could not receive treatment, or relatives being left waiting for contact that didn’t happen. The latter was particularly common after patients were discharged from hospital, when relatives found themselves suddenly alone with their caring responsibilities.

...like that first night we came home from the hospital was just - we felt really, I was really sad, because suddenly when we left the hospital I realised we were on our own. (P9)

Several participants described the sense of panic they felt when left alone at a time of need.

...sometimes I'd look at her and feel desperate and just want a visit or someone, once a week or somebody to come round and say "there's nothing much we can do here really". And I knew that really, but it was just having that person, that professional to talk to. (P15)

Three participants described what a struggle it was to get their concerns about their family member taken seriously by professionals early on. Notably, all went on to assume high levels of responsibility and felt unconfident relying on healthcare services. For the five participants who had particularly difficult experiences, there was a pronounced sense of embattlement; a sense that they had to fight for their needs to be met.

I constantly had argumentative discussions, which is not pleasant, I'm not happy to do that, but I have no other choice, to be able to have these very hard conversations with those individuals concerned. (P14).

Several others experienced similar moments during caregiving and described the alienating effect of an unresponsive or preoccupied professional system. Particularly upsetting for three participants were conversations about the patient's prognosis and approaching death which were experienced as flippant or insensitive. Participant 15 described how she went to collect her mother from hospital and overheard the doctor telling her she had cancer: *"it was just, it was so cruel, so unnecessary"*.

Psychologically, such experiences left participants with a sense of the momentousness of their situations going unacknowledged or thoughtlessly dismissed.

You do feel hurt because you feel you're doing everything you can, and you want to make that person comfortable, and you can't even get the smallest thing, you know, because somebody is not willing to give it to you, I don't know, because you don't care about cutbacks at that stage... (P9)

They could also evoke feelings of anger and frustration.

They'd say "you need to do X", then you go to the next one, "you need to go to this person", so you're building your anger as you go through those agencies, so by the time you get to the final one you're up to your maximum. (P14)

1.2. Being held in mind

Feeling able to rely on professionals contributed not only to a sense of security that patients were being looked after (as described above), but also to a feeling amongst participants of being looked after themselves. Often there was one person (or service) in particular that participants felt was looking out for them. Participant 13, for example, described how much he valued the support provided by his mother's GP.

Her empathy, you know, her support, her understanding, was exceptionally one of the best ever I have come across. You know, and I feel that, you know when I see her, I'll always remember my mother. (P13)

Simply knowing this meant a great deal, even for those who felt otherwise quite unsupported, and ostensibly little things could make all the difference. In particular, participants wanted someone simply to take the time to understand what they were going through.

I think it makes the whole thing – like [hospice nurse], she always used to call and things and that really helps you. Even that, saying "how are you finding it?" kind of thing, that's – you know, at least I can kind of open my heart, tell her what I'm feeling or whatever. (P7)

This did not necessarily mean that relatives wanted someone to enter into their feelings with them; in fact, participants often valued it when professionals were

able to “*hold their own*” (P6) and related to them with warmth or even joviality. Just as they wanted to be heard, participants appreciated it when professionals took the time to explain things to them and made them feel included. Several participants spoke about how the hospice staff took the time with them and two contrasted this with how they were treated in generalist medical settings.

You could have been walking along the ward and they [hospice staff] could have been going off somewhere, you spoke to them and you could have spoken to them for 10, 15 minutes and they would have still been there with you. Whereas in another hospital you would have been brushed aside and you would have got two words out and they would be gone and you’d be none the wiser. (P2)

Almost all the participants also mentioned friends or family as a source of mutual support, although the prominence of this theme varied widely. On the whole, those with the greatest responsibilities, who tended to have more negative experiences, spoke less about their support networks. In contrast, notable in two interviews – which were, overall, less negatively charged - was the repeated use of the pronoun “we”. Being able to share decisions with trusted others was reassuring for participants and helped mitigate the burden of responsibility and the sense of aloneness that otherwise threatened.

If you’ve got other people in the process it does help, because it’s sort of shared isn’t it. Just someone to talk about things with, and share experiences with, it’s very important actually to have other people. Because otherwise it can be just too scary...(P10)

...she [friend] used to ring me sometimes and ask how [wife] was, so...they was all helpful. And I could talk to them, and then I felt at ease. (P11)

1.3. Losing a relationship

A common theme across most interviews was a sense of having lost the patient, in some ways, before they died. Participants spoke about the pain of

witnessing the physical and mental decline of their family member and the shock of realising “*that’s not him/her*”.

His whole personality changed, he went very very into himself, quiet, he wasn’t sleeping, he used to sit in that chair 2-3 in the morning. (P5)

Two participants talked explicitly about grieving before the death. Often, participants’ descriptions of their family members suggested a sense of death’s presence even in life.

How he ended up weight-wise I don’t know but it was just like, skin over a skeleton frame. (P2)

Participants also experienced a loss to their relationship with their family member on account of their caregiving responsibilities. Becoming a carer meant navigating new boundaries in the relationship, both physical and emotional. Often relatives were involved in intimate aspects of care such as washing and dressing. This could be upsetting for patients and difficult for relatives in turn who did not want to compromise their family member’s dignity. Similarly challenging were times when patients were reluctant to accept help and when participants were on the receiving end of their frustration and anger.

[Uncle] did get me down quite a few times, because when they’re in pain and their attitude changes and they might start shouting at you, you know I think it’s those things that wear you down, and that’s when you sort of like break down. And I used to be in tears sometimes from the way he’d spoken to me. (P2)

Participant 7 felt that her preoccupation with the responsibilities of caring detracted from her capacity to enjoy her relationship with her mother.

It was hard because me and my mum were really close, we used to have a lot of conversation but during that time there was no conversation or anything, it was always just “am I doing it right?” and things (P7).

1.4. Intimacy

Despite the challenges of caregiving, participants also described ways in which they continued to enjoy their relationship with their family member. In fact, for some, the awareness of the approaching death spurred a resolve to make the most of the time they had together. Several participants mentioned rituals and routines which, so resonant of their family member's character, meant a great deal to them at this time.

But really and truly all I did when I went over there was have quality time with him. Take him down to the pub to have a bite to eat. We'd go down there and he'd say "can I have...", "[brother] you can have whatever you like". (P6)

For some, caring itself also afforded opportunities for renewing ties and deepening relationships. Participant 9 described how much she valued living with her sisters for the first time since childhood, and the deeply intimate moments they shared together.

...then we'd both go and take a sofa each and go off to sleep, it was just really nice, you know sort of like camping out or something when you were kids. It was just like, we haven't been like that together for so many years, we were just really close. (P9)

Several participants also developed close relationships with professional carers and experienced a connection through their shared task.

...if she [carer] saw my mum upset she would connect it with something in her life, and then she'd cry, and so (laughter) I was supporting her a bit in the end I think. No but it was good, it made, I don't know, it just made you realise that everything, you know that things happen everywhere, so you're not on your own with it. (P15)

Category 3: Death

This category is concerned with participants' thoughts about the approaching death of their family member and about mortality more generally. Themes illustrate the anxiety such thoughts could elicit and the ways in which this was managed during caregiving.

3.1. *Knowing but not knowing*

A prominent theme across almost all the interviews was the inability to fully comprehend the imminence of the death. Some participants described this in terms of a gap between knowing “academically” or conceptually, versus knowing “emotionally”.

Even though we were there and we knew she was going to die, we didn't think she was going to – realistically, emotionally we didn't know she was going to go. Academically you know lots of things. So, even when she came home we just thought, you know, what does death actually mean? (P12)

Others referred to it more indirectly, through phrases such as: “*we knew in the background*” (P12), “*I think in the back of your mind you know*” (P2) and “*in a round-about way I suppose I expected something to happen*” (P11). Several participants described a kind of intuitive, felt knowing that was hard to pinpoint or fully acknowledge, referring to a “*sixth sense*” (P1), knowing “*in my heart*” (P5 & P6) or having a “*feeling*” (P7). Several also said that despite knowing what was going to happen, they still clung to “*that slight bit of hope*” (P2) and almost invariably the death itself came as a shock. Three participants felt that they “*blocked out*” their feelings in order to cope in their caregiving role.

People say they build a wall, and I think that's what I done...because if I started to show weakness then there was a good chance that I would just crumble. (P2)

3.2 Repeated confrontations with mortality

The dissonance participants experienced in thinking about the death was mirrored in the non-linear fluctuations in understanding and readiness over time. Around half of the participants referred to sudden moments of realisation when they were jolted into an awareness of their family member's impending death. Interestingly, these moments were not necessarily in response to medical predictions but could be triggered by more subtle signs in the patient's condition and things said or unsaid. In the quote below, Participant 6 describes her internal response to a professional carer's hope that her brother would get better.

On the Sunday when I went to see him and he was standing in his flat and I just looked at him and...in my heart of hearts I thought "it's not going to happen [carer], he's dying", I could see he was dying. (P6)

For some, these were moments of helplessness as they watched their family member fading and death approaching.

It was just actually seeing her – they'd got the bed in and everything – seeing her in that bed, knowing how well she was; she was always very very strong, and just seeing her lying there and not able to do anything, you know. That was...that was awful. Having to go through that. (P3)

A few participants described their shock at the rapidity of their family member's deterioration. For others, the trajectory was more prolonged and several participants described the turmoil of repeatedly "bracing" themselves for the moment of death and then "deflating" when it did not happen. Three participants said that this happened so many times that they began to disbelieve the signs. For Participant 8, this made the moment of the death a devastating shock.

Because he [nurse] said 28-48 hours, so I was, I thought he [husband] could pull through like the last time, if he's given him so much time. Because it's like you get used to him having infections so often you see. (P8)

Participant 10, however, felt that this pattern – whilst challenging at the time – helped her to prepare.

...there'd been so many times when we'd been shocked by what could happen that we were prepared, we'd been through the whole range of emotions, we'd been through it all kind of thing, so that when it did actually happen we were quite well prepared, we were quite able to take it in. (P10)

In this highly uncertain context, professionals' comments carried great weight for relatives. Participants wanted professionals to speak openly and honestly to them about their family member's prognosis. In contrast, oblique or ambiguous communication contributed to a sense that things were being withheld and could add to the confusion.

And you know, and basically saying it how it is, kind of thing...I think that's so important. You know, although you know kind of in the background, sometimes it helps when someone says it. You know, this is what you can expect. (P7)

At the same time, medical predictions were not always correct. Participant 14 described two incidents when comments by professionals provoked immediate and unnecessary panic within his family. He emphasised the importance of professionals qualifying uncertain predictions which could otherwise be taken as definite.

3.3. Protecting family members from existential suffering

As well as their concern that their family member did not suffer physically, relatives wanted to protect them from emotional or existential suffering. This theme came up in almost all of the interviews: participants spoke about wanting to give their family member hope, trying to disguise the prognosis or assuage its emotional impact, and comforting their family member through distraction or, less commonly, confrontation. Participant 1 described how she talked with a psychologist by her

mother's bedside about her fear of death, "*hoping that...it may help, I don't know, ease her mind.*" Participants often tried to hide their own knowledge or fears from their family member, not wanting them to give up hope. Two participants acted as translators for their families at medical appointments and both described filtering what was said: "*You never gave a literal translation. You had to temper the bad news*" (P12). A further two described their relief that professionals did so when disclosing the prognosis, showing in their manner an understanding of the impact of what they were saying.

I imagined it would be a question of, you know, very coldly "you've got cancer". I know they're not like that but you think in the back of your mind you know "you've got cancer, you've got so many months to live, there's nothing we can do so cheerio", but he had a wonderful manner, he was very reassuring. (P4)

Many participants were afraid of their family member dying on their own or being left in a state of fear and some went to great lengths to prevent this – for example, by sleeping on sofas next to them:

...when I got back he was crying, on the settee, I said "what's the matter", he said "I got frightened", I said "that's it, I'm not even going round the corner no more". (P5)

In turn, knowing they were present during their family member's dying, either physically at the time of death or through a more longstanding presence during their illness, was a source of comfort.

3.4. Thinking about mortality

Several participants said that the death of their family member put them in touch with thoughts about mortality, including thoughts about their own death.

And when it happened it was oh god, this is happened and it makes you think anything can happen at any time, it brings it home that, you know, you're not here forever. (P3)

This was a relatively less prominent theme but was touched on or alluded to by seven the participants. Three of these spoke more extensively about the place of death within their values or worldviews and the importance of those values in overcoming fear.

Trying to be there for somebody, comfort them. You know, and not sort of giving in to fear. Because if you, if you're fearful, you've already sort of lost your life in a way. You know, if you're so gripped with fear about everything, you're already kind of dead. (P10)

One participant, however, felt more “lost” and expressed feelings of hopelessness about her future.

Category 4: Meaningfulness

This category contains two themes highlighting the ways in which caregiving was often experienced as a deeply meaningful endeavour, which, despite its challenges, also had positive dimensions.

4.1. Finding meaning and solace in caring

All participants expressed their commitment to looking after their family member and there was a sense that doing so took absolute precedence over other commitments. Despite its challenges, most relatives described positive aspects of caregiving. Participants often spoke about wanting to give something back to their family member and being able to do so was a source of comfort to them.

I thought to myself yeah, you've done things like that for me, it's my turn to help you out and look after you and support you. (P11)

...it just felt, it felt right, you know and we felt actually privileged to be able to help somebody in that way, you know. (P9)

In five interviews, these positive aspects of participants' stories came through particularly strongly. There was a sense in these interviews that participants felt confident and supported in their roles, were not over-burdened with responsibility and had the mental space to reflect on the value and import of what they were doing. These participants were also more able to enjoy the time they spent with their family member.

Of these five, four described how their religious faith was a source of strength for them. These participants connected their caring responsibilities with the values enshrined in their faith and drew comfort from a religious understanding of death.

Because I know, but I wanted, I wished that she did, I wished that she had that conviction but I don't think she did really. I knew, yeah, that she wouldn't have any more suffering, and she'd be alright. (P1)

And you know, but before you die, you know, you have to do everything possible. If you have a mother or father, you need to look after them. If you're going to the haven, and you support one of your parents, either mother or father, you know, then you have a good chance to succeed and go into the haven. (P13)

Two participants described specific moments of religious or spiritual significance in the final moments of their family member's life; signs to them, for example, that other deceased relatives had come for them.

4.2. Acceptance and gratitude

A common (although not universal) theme concerned participants' appraisals of events or situations from an alternative, more positive perspective. Many participants said they were glad their family member did not suffer. Others commented on the gradual nature of the illness, which gave them time to adjust and

opportunities to say things they wanted. Yet others were glad that their family member was not in a state of mind to fully comprehend what was happening. Often these comments came in the form of a moment's reflection in participants' narratives (although much less so for those who had a more difficult time and for whom the loss was still raw). It seemed that being able to entertain a different perspective was helpful, as illustrated in an incident described by Participant 6 when her brother's medication did not arrive. Rather than dwelling on and worrying about the situation, she reappraised it as one which had granted her an extra few hours with her brother.

And, quite rightly, after speaking to my younger brother, he said well...they could have administered that drug at 2 o'clock, he could have gone into a coma or to sleep, and we wouldn't have seen him till 5 o'clock. So we can look at it, we can only look at it from the positive side, all of us, we all agree we were lucky to have those last few hours with him. (6)

Three participants spoke more extensively about finding a level of "acceptance" which brought with it feelings of gratitude for how things happened or more generally for the family member's life. Participant 6, for example, described how her previous encounters with death gave her a sense of gratitude for life and a motivation to "live for today". Participant 13 spoke about the importance for him of accepting that "life is not always the way you expect it" and "we don't have the authority to decide or dictate what we are going to do".

Discussion

This study explored the emotional challenges faced by relatives caring at home for a dying family member, using existentialism as a broad theoretical framework within which to conceptualise themes in participants' narratives. Themes were organised into four categories based on Yalom's "existential conditions" – responsibility, isolation, death and meaningfulness (Yalom, 1980). In this section, the

findings are discussed in the light of the theoretical framework and prior research. Although the four categories are discussed separately, there is a degree of overlap between them which reflects their interdependency within Yalom's framework.

Responsibility

Participants in this study frequently took on high levels of responsibility in caring for their family member. This is consistent with previous studies of home caregivers and highlights the demands placed on relatives in this context (e.g. Brobäck & Berterö, 2003; Linderholm & Friedrichsen, 2010; Wennman-Larsen & Tishelman, 2002). For some, who felt unsupported by professionals, the responsibilities of caring were experienced as burdensome and overwhelming. Particularly detrimental for relatives were perceived failures in the coordination of care. In a focus group study, Teno et al. (2001) found that "easing the burden of advocating for the patient" was perceived by relatives as a key feature of quality end-of-life care. The current study corroborates this finding and further highlights the crucial importance of readily available professional support (e.g. Munck et al. 2008; Proot et al., 2003). As noted by Teno et al. (2001), professionals can go a long way to mitigate the pressure on relatives by taking a proactive approach in coordinating patient care. This study also points to the power of practical support beyond its immediate tangible effects. Through their attentiveness to relatives' needs, professionals communicated a willingness to help which often meant a great deal. At a more general level, there was a sense that those who felt well-supported had more space (both practically and psychologically) to enjoy their relationship with their family member and find meaning in what they were doing. This raises interesting questions about the potential multiple benefits of practical (e.g. problem-solving) interventions of the kind described in Part 1.

Participants often experienced a compelling desire to “get it right” for their family member. Often, they were highly attuned to the patient’s needs and wishes; so much so, in some cases, that their lives revolved around their caregiving duties. It was striking how strong this narrative of “getting it right” was. In a study with current caregivers, Brobäck and Berterö, (2003) found that feelings of insufficiency were ubiquitous in their sample. Similarly, for participants in the current study there was a sense that doing a “good enough” job was never adequate. There is an interesting parallel here with the ideology of “the good death” in palliative care (e.g. Miyashita et al., 2008). There has been much debate within the literature about the concept of a “good death”, including acknowledgement of the heterogeneity in its conception across and within cultures. Despite recognition of the complex factors which frequently complicate the imagined ideal, the philosophy of the good death remains present in the goals and values underpinning end-of-life care (Watts, 2012). It is possible that the sense of responsibility experienced by participants in this study reflected a commitment to the idea of a “good death” that they must work to actualise.

From an existentialist perspective, the urgency attached to “getting it right” might be interpreted as fuelled in part by relatives’ awareness of the irrevocability of death. Drawing on the work of the philosopher Heidegger, Yalom (1980) suggests that a confrontation with death can uproot us from our everyday lives and transport us into the “ontological mode”, in which we become aware of ourselves as finite beings, responsible for our actions and the lives we lead. In this study, participants described vividly the sense of immediacy and momentousness that pervaded this time. It is likely that the patient’s approaching death amplified the import for relatives of their actions and decisions at this time, heightening the sense of

responsibility they felt in the light of their knowledge that time was limited. This was a responsibility to meet not just external demands but the demands of the conscience, enshrined in values, commitments and personal beliefs. In turn, this gave rise to self-doubt and sometimes guilt, as relatives looked to themselves to be their own guide in a context where there were often no rules for how to think and behave.

Isolation

For many, caregiving was at times a lonely experience. Relatives often felt a sense of loss on account of their family member's deterioration and their changed relationship with them. The concept of "anticipatory grief" (e.g. Johansson & Grimby, 2012) - that is, a state akin to bereavement that precedes the actual death – captures well the experiences of some participants. Often, however, the losses were more subtle and pertained, for example, to the erosion of familiar roles within the relationship. Carlander et al. (2011) suggest that caregivers face challenges to their own self-image as they adjust to the new role and the demands it places on them. This was borne out in the current study by the ways in which relatives had to master their inhibitions, bury their feelings and, sometimes, sacrifice their own needs in order to fulfil their caregiving duties. This could give rise to a sense of being distanced from the patient and, in some cases, alone. For some, there was a sense at times of being disconnected from the world and alone not just with their responsibilities but with their feelings; of being profoundly isolated, even when there were family and friends around. Such experiences seem akin to what Yalom (1980) calls "existential loneliness".

This perhaps also helps to explain the strong need for connection relatives felt at this time – both with their family member and those supporting them. According

to Yalom, it is through relationships that the gulf of existential isolation is, if not bridged, endured. In fact, despite - or perhaps because of - the patient's illness and approaching death, this could be a time of renewed or deepened intimacy.

Experiences of isolation were more pronounced in those who felt unsupported by professionals. In contrast, professionals could make a big difference by taking the time to understand what participants were going through. In essence, this was about empathy. The importance of empathic communication in this context is neither new nor ground-breaking (Farber et al., 2003; Steinhauser et al., 2000). However, this study highlights the power of empathic communication in mitigating feelings of isolation and the alienating effect for relatives of interactions which negated or belittled their subjective experiences. Participants in this study reported many positive experiences of interactions with healthcare professionals. There were, however, some notable exceptions. Importantly, just as an individual could be perceived as insensitive, so a healthcare system could be perceived as preoccupied or neglectful.

There are numerous ways of understanding how and why failures in empathic communication come about. One possibility is offered by McNamara (2004), who argues that with the increasing emphasis placed on patient choice and autonomy in healthcare, palliative care professionals may find themselves taking a less "involved" approach, focusing on the concrete tasks of symptom management rather than the uncertain and potentially unachievable goal of actualising each patient's "good death". Kleinman (1988) argues that the language of medicine can be a narrow and restrictive one, coining the term "empathic witnessing" to describe a way of relating which is open to and respectful of patients' subjective experiences. It is perhaps noteworthy that in this study professionals were not seen as interfering or imposing

when they did become more involved; on the contrary, such “interventions” were invariably welcomed.

Death

As the patient’s condition deteriorated, relatives struggled to come to terms with their knowledge of the approaching death, the thought of which was almost incomprehensible. Within the palliative care literature, death anxiety is a relatively underexplored area and most studies to date have focused on the patient’s perspective. One study by Adelbratt and Strang (2000) involving patients with malignant brain tumours found that death anxiety was also common in their next of kin. As in the current study, this anxiety pertained both to the patient’s approaching death and relatives’ heightened awareness of their own mortality.

At the same time, relatives felt they had to bury such thoughts, both for their own sake and in order not to burden their family member. In a study with dying patients and their next of kin, Sand and Strang (2006) found that the nearness of death often made it difficult for people to share their thoughts and feelings with one another. Similarly, in this study, relatives felt they had to protect the patient and stay strong for them. Several participants said that whilst caring they had to block out the thought of their family member’s approaching death in order to function as a caregiver. They could not let themselves enter fully into the reality of what death meant, else they might, as one participant put it, “crumble”. This finding supports the claim by Hebert et al. (2006) that “preparedness” in the context of end-of-life care is a complex and multidimensional construct, comprising cognitive, affective and behavioural domains. Many would argue that a loved one’s death is something for which one cannot ultimately prepare (Farber et al., 2003). From an existentialist

perspective, to repress thoughts about death may be a defence but it is a universal and necessary one; to enter into them too deeply or too long is terrifying. This idea is also central to the “dual process” model of bereavement, which emphasises the importance and functionality of both emotional processing (or “grief work”) and emotional avoidance; the latter making room for more action-oriented, “restorative” coping processes (Stroebe & Schut, 1999).

Meaningfulness

Yalom (1980) contends that in the “ontological mode”, possibilities open up before us to embrace what is most meaningful to us. For participants in this study, the end-of-life period was one of heightened meaning; several described being in touch with their values and a sense of meaning that transcended their normal lives. This finding corroborates past research highlighting meaningful positive dimensions to caregiving (Milberg & Strang, 2003; Wong, Ussher, & Perz, 2009). Milberg and Strang (2003) conceptualise meaningfulness as one facet of “sense of coherence” (alongside comprehensibility and manageability) – a psychological construct known to predict coping (Antonovsky, 1987). In this study, it was notable that participants who spoke more about the meaningfulness of caregiving - including those in touch with the values of a religious faith - tended to have more positive experiences overall.

Frankl (1946) writes about the importance of a sense of meaning or purpose in enabling us to endure suffering; furthermore, he argues that humans have a remarkable capacity to find meaning even in and through suffering. This was borne out in this study by relatives’ commitment to their family member’s care and the sense of comfort that came with knowing they did all they could. In his personal

testimony of being a caregiver, Kleinman (2009) writes of caregiving as a moral activity, a journey through which a person emerges “more human” (Kleinman, 2009). In the current study, there was a clear sense for some of having been through a journey, a test almost, for which they had to draw on their own inner strength and find their own rewards.

In this study, there was little sense for participants of meaninglessness; on the contrary, this was a period of heightened meaning. Whilst this can be understood - and indeed fits well - within an existentialist framework, it is worth flagging the relative absence of the negative pole, which might be expected to be a feature of some people’s experiences. It is possible that our methods did not tap into feelings of meaninglessness, which might have been difficult for participants to describe. In addition - and an important consideration when it comes to the generalisability of the findings - the assumption of meaninglessness is based on a secular worldview, and may not fit for those who follow a religious faith.

Limitations of the study

From a methodological perspective, the retrospective nature of the interviews meant that participants’ accounts may have been subject to distortion over time. The nature of semi-structured interviews also allows for the possibility that aspects of participants’ experiences were omitted or emphasised during data collection. In this study, credence was given to participants’ subjective accounts – we did not seek to verify them through, for example, checking medical records. This approach was based on the assumption that these accounts reflected participants’ subjective realities, irrespective of alternative perspectives. It is important to recognise,

however, that the picture we received was inevitably shaped by the context of the study and was, therefore, necessarily incomplete.

Similarly, the study was based on a small sample of participants from one urban setting and the findings may not be generalisable to other contexts and populations. The sample was biased in its composition towards older, female participants. In addition, the majority of participants were White British, a proportion that does not reflect the diversity of the local population. Lack of access to interpreters meant that we were unable to include people who did not speak English. However, the aim in this study was not to attain a representative sample but to draw insights from a detailed analysis of a small number of participants.

In the chain from subjective experience to analysed data, the researcher also has a shaping influence. In this study, a theoretical framework was used to make sense of the data. Whilst on the one hand this afforded structure and insight, any framework has its limitations. In this study, Yalom's four categories were construed broadly to encompass diverse aspects of participants' experiences, some of which were more pertinent to the core theoretical tenets of the model than others. The aim in this study was to stay close to participants' experiences, whilst at the same time using a theoretical lens through which to think about them. The findings are therefore not presented as a tight, unified model, and the framework does not claim to be either universal or complete. Although many of the themes came up in all the interviews, there were some participants for whom the framework seemed to fit better than others. The angle is a "psychological" one and seemed to fit best for those who talked more about their internal experiences. It also perhaps emphasises some of the more extreme experiences participants went through, both good and bad. In one

sense this is not surprising in a study focusing on emotional challenges, but it is important to bear in mind the variability of experiences.

Clinical and research implications

In a context of uncertainty, anxiety and responsibility, professionals' words and actions carried great weight for relatives. The findings of this study are consistent with and extend those of previous research in highlighting the multiple roles professionals occupy (e.g. Hebert et al. 2009). Funk et al. (2009) outline a model of support for caregivers underpinned by three facets of "security": security in the competence of professionals, security in the availability of support and security in being treated as an individual of worth. The findings of this study support this model in highlighting the importance for relatives both of feeling able to rely on professionals and of being treated as a person with unique needs and experiences rather than a "number", a cost, or a day's work.

The study illustrates the crucial importance of solid professional support for home caregivers. At a time when care is being relocated into the community, there is a need to ensure that caregivers are seen not just as colleagues within the medical system but recipients of care themselves. With increasing value being placed on home-based care in national and local policies, it is important for services to be attuned to the potential implications for relatives and other informal carers. The rhetoric and discourses surrounding home-based end-of-life care may obscure the reality of the demands placed on carers, and may even add to the pressures of the role (Exley & Allen, 2007). Adequate provision needs to be made to ensure relatives are not overburdened with responsibility and feel sufficiently confident in their roles. A proactive approach should be taken to ensure relatives are clear about the limits of

their responsibility and avenues for additional support. With all their energies directed at the patient, relatives may find it difficult to express or even think about their own needs. Professionals should take the initiative in allowing them to do so, talking to them about the challenges of caring, and equipping them with relevant information, skills and practical aids.

This study suggests that relatives benefit from the opportunity to build a relationship with a professional who knows them and the patient. In contrast, multiple agencies and contacts can be confusing for relatives, and may leave them in the position of care-coordinator. This speaks to the importance of communication between professionals in different organisations, and the potential value of a single point of contact. Healthcare professionals should also be alert to the potential impact on relatives of systemic failures, which may go beyond practical inconvenience and destabilise their trust in services.

Healthcare professionals may find it helpful to hold in mind a framework such as the one provided here in their interactions with patients and relatives. Much of what is described may well be familiar to those working in the field, but the mental framework provided by a theoretical model may be a useful aid to clinical practice. In particular, the themes presented here highlight the profound emotional and existential challenges relatives face in coming to terms with and preparing for a family member's death.

This also raises the question of whether these are issues that ought to be addressed through formal psychological interventions of the kind reviewed in Part 1. It should not be assumed this is necessarily the case; caregivers are not patients, and may not want or need to talk to a professional about their emotional experiences. In

fact it was notable in this study that professionals could do much to assuage anxiety through more “informal” means e.g. providing an opportunity to be heard and reassuring relatives that they were doing all they could. At the same time, there may be scope for more formal approaches to incorporate some of the themes presented here. Of the four types of interventions outlined in Part 1, bereavement/meaning-based approaches address these themes most directly, and this study attests to the sustaining effect for carers of being able to access a sense of meaning at this time. Other intervention-types (e.g. psycho-educational) might also help to normalise some of the internal struggles carers may face.

Professionals should also be alert to the unasked questions relatives may have, particularly around the patient’s prognosis and death, and maintain clear and unambiguous communication around these issues. In a context where uncertainty is the norm, it may be helpful for professionals to discuss this very issue openly with relatives. On a more speculative note, it is possible that staff and relatives would benefit from acknowledgement of the multitudinous factors which may impede a “good death” and, perhaps, the impossibility of getting it perfectly right. This point is made with caution as there is also a risk, as McNamara points out, of the “good enough death” ideology licencing the prioritisation of medical issues at the expense of families’ emotional and spiritual needs (McNamara, 2004).

This study was broad in scope and there is potential for future research to look in more detail at each of the four categories of themes. It would be helpful to carry out studies in other settings and at other time-points in order to improve the generalisability of the findings and to look at how relatives’ experiences change over time. The extent to which participants’ experiences of palliative care effect their adjustment during bereavement may be a particularly fruitful avenue for future

research, and has received relatively little attention hitherto (Hebert et al., 2009; Ylitalo, Valdimarsdóttir, Onelöv, Dickman, & Steineck, 2008). More specifically, studies might look at which aspects of relatives' experiences during palliative care are most problematic for subsequent adjustment, and ways in which professionals can address them.

Future research might also explore the perspectives of staff working in palliative care, particularly around incidents where care or communication is perceived to have gone awry by relatives. This would help to shed light on some of the barriers to effective care and to forestall some of the negative experiences reported in this study. It might also be interesting to look at whether any of the experiences reported by relatives are shared by staff. Working in a context where death is ever-present, it seems likely that staff will experience some of the same existential anxieties as relatives. If so, a better understanding of this may help to improve the support provided for professionals.

As discussed in Part 1 of this thesis, there is also a need for more research into ways in which relatives can be supported in end-of-life care. This study suggests that interventions might usefully consider the existential anxieties faced by relatives at this time. The literature review in Part 1 indicates that few evaluated interventions have focused directly on these issues; further research is needed to explore how they can do so most effectively.

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Part 3: Critical Appraisal

Introduction

This section is a reflection on the process of carrying out the empirical study and literature review. I aim to highlight and discuss some of the key challenges I faced, to explain further the decisions I made, and to consider some of the limitations of the research. I will also discuss some of the wider methodological and contextual issues relevant to research in this field.

The empirical study

Reflexivity often has an important place in qualitative research, serving to draw attention to the shaping influences on the research (Willig 2008). This section is divided into two parts based loosely on Willig's (2008) distinction between personal and epistemological reflexivity. The first is a reflection on how my personal experiences both prior to and during the research influenced its development, and how I was affected in turn by the research. The second focuses on the evolution of the study in terms of its research focus – in particular, the incorporation of theory in the analysis and interpretation of the data.

My background and experiences

My decision to pursue this research project, and the direction in which I took it, were inevitably influenced by my interests and experiences. In preparing for the project I spent time reflecting on the potential impact, both on the research and on myself, of my personal experiences and theoretical leanings. It was not without trepidation that I am embarked on the project, anticipating as I was the “immersion” that often comes with qualitative research (e.g. Holloway & Wheeler, 2010) and the emotionally laden nature of the subject matter. I was concerned, too, that my own memories of the death of a close family member might compromise my ability to

remain neutral in eliciting and interpreting participants' stories. This is not to say, however, that I viewed my connections with the topic as necessarily being a hindrance. Within a contextualist epistemology, personal experience is not seen as "unwanted baggage", clouding the lens of analytic enquiry, but as a potential source of interpretive insight (e.g. Fischer, 2009). Arguably, any researcher brings ideas, values and roles of their own to the process (Krefting, 1991); direct acquaintance with the subject matter may in fact serve to challenge one's preconceptions and heighten self-awareness.

Much has been written within the literature on qualitative methodology about the importance of "bracketing". In essence, bracketing involves identifying and attempting to suspend one's preconceptions, thereby limiting their undue influence on the research (Fischer, 2009). There is much controversy over whether bracketing is truly possible, what should be bracketed and at what stages of the research process (Fischer, 2009; Tufford & Newman, 2010). As noted in the empirical paper, bracketing is not about shedding one's ideas in the interests of objectivity; in fact, it can also facilitate thoughtful and reflective engagement with the data (Tufford & Newman, 2010). Its importance lies in ensuring that this is a transparent process, in which the possibility of alternative perspectives (amongst both researchers and readers) is allowed (Fischer, 2009).

Various bracketing "techniques" have been described, commonly involving a process of self-reflection (Ahern, 1999). One way in which reflexive bracketing can be facilitated is through discussion with others (Tufford & Newman, 2010). In this study, a collaborative approach was taken throughout the research process. Before embarking on the project I discussed my experiences and theoretical biases in supervision and with the wider research team. During data collection, regular

meetings were held in which selections of transcripts were read and discussed. As a team, we endeavoured to maintain a reflexive stance throughout data collection, bracketing our expectations and even the initial research questions as data emerged that challenged our initial ideas (this is discussed in more detail in the section below).

During interviews, I was both helped and hindered in my efforts to bracket my ideas and preconceptions by my clinical training and experience. Particularly helpful was my experience working in a systemic and narrative model, which advocates a “not knowing” and radically curious approach to therapeutic interaction (e.g. Ekdawi, Gibbons, Bennett & Hughes, 2000; White & Epston, 1990). The concept of countertransference also helped me to reflect on my feelings and responses during and after interviews, in order to aid my understanding of participants’ experiences and to consider what I might be adding to them (Hiemann, 1950). On the other hand, having been schooled in a discipline which recognises the limits of self-awareness, I was often unsure of my success in bracketing, and sometimes it was my clinical experience itself that needed bracketing. As I was hearing participants’ stories, I often felt the tug of the therapist in me. Several times the research team identified moments when I had suggested links participants had not themselves voiced. Given the sensitive topic matter, I think it was important to create a space in which participants felt comfortable to talk, and my therapeutic skills undoubtedly helped me in this. At the same time, there was a balance to be struck between responding with warmth and empathy and maintaining a sufficiently neutral, non-directive stance, so as not to artificially shape the interview.

Tufford and Newman (2010) suggest that reflexive bracketing also serves a protective function for the researcher immersed in an emotionally demanding subject matter. They note the dangers of the research becoming burdensome and the

concomitant narrowing influence on data collection and interpretation. It was important to talk about the emotional impact of the research on me and this was acknowledged from the outset.

My experience of conducting the interviews was actually less harrowing than I initially anticipated. Many people had positive experiences of professional services and were keen to express their gratitude for the support they received. Others, who had less positive experiences, seemed to find some comfort in being able to express this and contributing to a project which aimed to improve the situation for other caregivers. From the perspective of existential psychology, taking part in the study was perhaps another small way for participants of transforming their hardships into something meaningful.

Nevertheless, there were times when I felt drained by repeated immersion into the subject; times when part of me wished to escape from it all. Like some of the participants I interviewed, I found myself thinking more about death whilst conducting the research, and sometimes this did feel burdensome. I was helped in dealing with this by maintaining a self-reflective stance and sometimes choosing to put the project aside. It was striking how differently I was then able to think about the material when I came back to it afresh. It is, however, entirely possible that these negative feelings contributed to a degree of avoidance during data collection. In team discussions it was noted on more than one occasion that some interviewees tended to focus heavily on practical details rather than describing their thoughts and feelings. I expect this was partly due to participants' protecting themselves from painful feelings; it is more than likely, however, that I also held back from probing too deeply into particularly painful areas.

Like the participants in this study, I was also spurred on by the hope that what I was doing might make a difference to others. In *Staring at the Sun*, Yalom (2008) uses the term “rippling” to describe the way in which even after their death, someone’s life can leave a mark on the lives of others through generations to come. Knowing this, Yalom claims, is a source of comfort in the face of death anxiety, and one way in which the idea of death can be rendered meaningful. In some ways, this research project might be thought of as an example of “rippling” in action. I was touched by the stories participants chose to share with me and often found myself forming vivid impressions of their family member. Their stories will certainly stay with me and hopefully will touch the lives of others as well. In the same way, perhaps, undertaking this research was one way in which my own past experiences were channelled into something creative and productive, with a wider resonance beyond my own life.

The analysis and incorporation of theory

Something I was often conscious of was the risk of shoehorning data into a framework that did not fit. In fact, the incorporation of existentialism as a central focus of the study occurred not at the outset but further down the line. Whilst this might seem like a rather post-hoc approach, the use of theory in this way is not unusual in qualitative research, which by its nature is exploratory (Sandelowski, 1993). The format of empirical papers is, Sandelowski suggests, more suited to quantitative studies and the hypothetico-deductive method, implying as it does a linear process flowing logically from theory and prior research. In qualitative research, however, the process is often more fluid.

The initial impetus for the project actually came from the hospice, and anecdotal evidence within the research group suggesting that family members of patients receiving palliative care at home sometimes misconstrued the nature of medical interventions at this time. In particular, some relatives linked the administration of anxiolytic or “sedative” drugs to the loss of consciousness of their relatives. Whilst such drugs do have a “sedative” effect, in terms of reducing levels of arousal, their purpose is not usually to elicit unconsciousness but to ameliorate discomfort and anxiety (Muller-Busch, Andres, & Jehser, 2003). For some relatives, however, the drugs were seen as the proximal cause of the patient’s death. This evoked anger at health professionals, regret that the loved one lost consciousness too soon and guilt at being a party to the decision to administer the drugs.

The initial idea was therefore to focus on the end-stages of the patient’s life, including relatives’ understanding of the rapidly changing events leading up to the death and the meaning for them of professionals’ interventions at this time. It soon emerged, however, that the period immediately preceding the death seemed to be less important for participants than we had initially anticipated. Instead, we were hearing stories that described the whole trajectory of caregiving. Indeed, for many participants the actual temporal course of events did not seem to map onto linear changes in their experiences; rather, the whole duration of caregiving was experienced internally as one of constant shifts and changes. The idea of delineating a particular period based on its temporal proximity to the death misrepresented participants’ experiences from the outset. A decision was therefore made to look at participants’ experiences across the whole duration of caregiving.

This broadening of the temporal scope of the research, together with preliminary analysis of the emerging data, led to a more explicit focus on existential

issues. During the early stages of the study a number of relevant theoretical approaches were borne in mind. Conscious of the weaknesses of previous qualitative studies in the field, we were keen to make use of theory in the interpretation of the data, but did not wed ourselves to any specific framework. Several members of the research team were familiar with the framework of existential psychology, and as we read the transcripts we began to notice resonances with Yalom's four existential conditions. In fact, my supervisor and I found that holding this framework in mind made the transcripts more memorable and afforded new insights into the data. After discussion amongst the research team it was felt that existentialism provided a useful framework within which to organise and makes sense of the material. By incorporating a theoretical framework in this way, we aimed to carry out a richer analysis, and one which provided illuminating insights into participants' accounts.

Historically, the place of theory in qualitative research has been another area rife with controversy (Sandelowski, 1993). Some have argued that qualitative researchers should be naïve to what has come before in order to be guided as much as possible by the data (e.g. Glaser & Strauss, 1967). Although often quoted, this position is no longer widely held and there are strong arguments for drawing on the literature - including the theoretical literature - at multiple stages of the research process (Flick, 2009; Sandelowski, 1993). The reflective and collaborative stance we endeavoured to maintain was, however, important in providing a check on any procrustean manipulation of the data to suit the theory. In particular, during the analysis, it was helpful for me to receive feedback from members of the research team (some of whom were less well acquainted with the theoretical framework) about the cogency of the proposed categorisations. Immersed in the data, I did find myself wondering at times whether the framework I was developing would ring true

for others. Working out how exactly to use the more theoretical aspects of Yalom's framework in the discussion and interpretation of the findings was another conceptual challenge, and again I was cautious of over-relying on aspects of the model that felt strained. My approach was to try and give priority to the data itself, and to bring in relevant theory (including from other theoretical models) as an additional aid to interpretation. It was helpful to have this both questioned and affirmed by the wider team as I proceeded.

In addition to the consensus approach described above, another credibility check (Elliot et al. 1999) used in this study was to invite participants to provide feedback on a preliminary analysis of their interview. Only about half of the participants responded to this invitation and those who did were generally happy with the summary. These summaries were written at an early stage in the analysis, before the incorporation of theory. Krefting (1991) suggests that this is an appropriate stage to elicit participant feedback as the later stages of the analysis tend to involve higher-order conceptualisations which may be more remote from participants' experiences. On the other hand, this meant that participants were not able to provide feedback on the proposed framework (although aspects of it featured in their summaries). In retrospect, it might have been helpful to share this framework with participants in order to gauge the extent to which it resonated for them, and to look at any individual differences across the sample.

On a related but divergent note, of those who responded to the invitation to provide feedback, many commented on how helpful they had found the interview and, in some cases, the written summary. Relating this to the study's findings, it is possible that for these participants, the opportunity to have their experiences listened to and thought about was a validating experience, and maybe even helped to mitigate

their feelings of isolation. Several participants said that the research process had actually helped them to come to terms with the death of their family member. This raises interesting questions about the potential therapeutic benefits of a one-off meeting for those recently bereaved.

The literature review

In this section I discuss and reflect on the limitations of the review, the conceptual and methodological challenges I encountered in carrying it out, and some of the questions and controversies arising from it. In doing so, I aim to draw out some of the wider issues pertaining to research and clinical practice in the field.

Shaping the focus of the review

The first stage in the process was to decide on a focus for the review. For me, this raised a number of challenges. One of the difficulties was finding a body of literature of a suitable size and easily identifiable nature to match the scope of the planned project. A number of potential topics were investigated and ruled out due to the lack of a circumscribed literature. One idea, for example, was to look at the impact of relatives' experiences of end-of-life care on their adjustment during bereavement. The difficulty was that research findings pertinent to the review question were embedded in a diverse range of studies which were hard to reliably identify. It is not impossible to carry out such a review, but it posed challenges that I could not address with sufficient rigor.

Intervention evaluation studies lend themselves well to review as they often comprise a clearly identifiable body of literature with common aims and methods. Having identified the literature on interventions for carers in palliative care, however, there was still work to be done in shaping the focus of the review. One challenge was

to ensure my review was sufficiently different from the existing reviews. From my initial scoping of the literature, I became aware of the diversity of interventions in terms of their aims and theoretical underpinnings. This was matched by a degree of vagueness in the clinical guidelines on support for carers, making it unclear what interventions in palliative care could or should hope to achieve. The existing reviews did not address these issues in any depth. Amongst other things, therefore, one way in which I wanted this review to be different was in its attempt to make clear the theoretical approaches and aims of the various interventions, and to compare the evidence base for different intervention types.

Another challenge concerned the parameters of the review. I was conscious that focusing on the palliative care stage excluded a wealth of literature - including intervention research - on the earlier stages of caregiving and on the period after bereavement. Despite the changes in relatives' circumstances, there is no inherent reason for dividing the literature in this way (something that became more apparent to me as I progressed with the empirical study). Nevertheless, some means of compartmentalising the literature was necessary in order to undertake the review. In addition, through its synthesising function, a review can act as a bridge to other research literatures. It felt important to draw attention to the parameters of the review in the discussion section, in the hope that its findings might be used flexibly and broadly rather than restrictively.

“Interventions” in palliative care

I was also conscious of focusing on the potentially restrictive construct of a “psychological intervention” when so much of what goes on in palliative care could be construed as this, albeit not formally described and measured as such. There is a

risk that research focused on the manualised and measurable downplays the kind of informal support routinely provided in a multidisciplinary team. The findings of the empirical study included several examples of small things said or done by professionals, which, at this time of emotional vulnerability, meant a great deal to relatives. Similarly, participants often benefited from the ongoing, holistic support provided by a whole service or network of services. Both the literature review and the empirical study highlight the practical and psychological barriers for caregivers in accessing formal support programs at this time. This is not to say that there is no place for formal, theoretically-driven interventions; on the contrary, this review shows that such approaches can add to routine multidisciplinary care. But there is a risk for reviews to read as definitive summaries of the evidence base, without due acknowledgement of the parameters imposed by operationalisation and study selection. In this field in particular, support comes in such varied and different forms that any delineation of manualised interventions cannot tell the full story about supporting carers at this time.

The “fit” between formal interventions and multidisciplinary end-of-life care may be a matter for future research. Studies such as the one presented here may help us to understand the ways in which relatives are supported locally by nursing and medical professionals, and to design interventions that complement and enhance this support. From an organisational standpoint, it is also important for staff to be supportive of interventions in order to maintain team cohesion and to prevent role ambiguity. This is important in any healthcare service, but perhaps particularly so in palliative care, where consistency and clarity of approach are so crucial.

Interpreting the findings – measuring benefits

In current healthcare research, the emphasis is very much on developing interventions which have a measurable impact. This review included only studies which used some form of quantitative measurement. There are advantages of quantitative methods, including the opportunities afforded for comparison and statistical analysis. It could be argued, however, that the search for measurable changes is a rather crude and possibly limited vision. It is possible, for example, that someone could derive benefit from an intervention but still report the same quality of life, or the same level of distress, several weeks later. The effects of an intervention may fluctuate over time and, especially in a context as complex and unpredictable as palliative care, may not be apparent on standardised rating scales. Such scales tend to focus on manifest symptoms and may not capture the nuances and personal meaning for people of their circumstances. This is part of a wider debate about the merits and demerits of standardised measures, but it is perhaps particularly pertinent in this context, where factors external to the intervention might play a particularly significant role in determining relatives' wellbeing.

Continuing this line of argument, it is also worth considering whether interventions are only of benefit if they result in lasting changes. Walsh et al. (2007) make the point that in medicine, a drug is not deemed ineffective if symptoms return when it is discontinued. In psychology research, however, there is usually an expectation that interventions will exert lasting effects. In this review, 7 of the 23 studies had follow-ups a month or more after the intervention. If the aim of intervening is to reduce distress and improve wellbeing, however, is it not still a worthwhile endeavour to do so for a few weeks, at a time of great need? The positive qualitative feedback given by participants in many of the studies suggests that

interventions may be judged as helpful at the time they are delivered even if they do not necessarily result in changed scores on post-intervention outcome measures. Again, the long-term effects of interventions may not be easily measurable; it is also possible that experiencing help at such a time may exert lasting effects after bereavement that do not translate into measurable changes in the rapidly changing context of end-of-life care.

It could be argued that it is not the remit of palliative care to take such a long-term perspective, and that doing so would detract from the immediacy of caregivers' needs in the present. These are interesting questions for discussion, which may be illuminated by future research. They are also relevant from a public-health perspective. Policy development is bound up with questions concerning the roles of different services and professionals, and the cost-effectiveness of interventions. None of the studies in this review included any cost-benefit analysis – again, this may be a worthwhile endeavour for future research.

The nature of the interventions

It is interesting to speculate about why certain kinds of interventions have received more research attention than others. Cultural factors may be important. All of the studies in this review were conducted in developed countries, predominantly the USA, Australia, and the UK. A recent UK survey suggests that death and dying are still “taboo” subjects (Dying Matters, 2011). Perhaps this is one reason why palliative care interventions have focused more on problem-solving and education rather than confronting thoughts and feelings about death. Critics of the “medicalisation” of healthcare argue that end-of-life care focuses too much on physical pain and medical problems, to the neglect of emotional and spiritual

suffering (e.g. Farber et al., 2003; Milberg & Strang, 2007). The interventions which perhaps addressed relatives' emotional and spiritual experiences most directly were those classified in the review as bereavement/meaning-based. As noted in the review, these interventions were in the minority. It is possible that in countries where the "medical model" still has a high profile, cultural norms contribute to cautiousness or even reluctance among researchers to develop more exploratory, emotionally-laden interventions. On the other hand, in the UK, the hospice movement has done much to broaden the scope of end-of-life care for both patients and relatives, including promoting greater attention to non-physical aspects of care. As the study by Kissane et al. (2006) reminds us, perhaps it is right to exercise a degree of caution in implementing interventions which may be experienced as destabilising at a time when people are at their most psychologically vulnerable.

One issue that perhaps complicates matters is the fact that the target population are not "patients" per se, and are involved in providing care themselves. Policy guidelines are clear that professionals should work with and alongside informal carers, involving them in decisions and respecting their choices. As the findings of the empirical study show, relatives are often involved in multiple aspects of patient care and feel a high degree of responsibility for their family member. It is possible that this quasi-colleague status of relatives contributes to a lack of clarity in the literature and policy guidelines about the role of professionals in supporting them. Certainly, working with relatives to optimise patient care can be seen as a form of support; many of the interventions in this review aimed to do just this. At the same time, carers have other needs beyond those directly relating to their caregiving responsibilities, which professionals are also in a position to address. Future research

might usefully explore how palliative care professionals experience their role in supporting carers, and how they navigate this dual aspect to the relationship.

The empirical study also highlighted some of the difficulties and complexities that arise at the interface between formal and informal care. Many of the participants welcomed at least some aspects of the caring role and wanted to retain it. Some participants felt well supported by their own “informal” networks and needed less input from professionals. At the same time, many caregivers described times when they felt unsupported and overburdened with their responsibilities. The challenge for services and professionals is to find a balance whereby caregivers feel supported and able to be with and care for their family member in a way that suits them.

Conclusions

In carrying out the empirical study and literature review, I faced a number of methodological, conceptual and personal challenges. In both projects, I found myself grappling with questions such as the role of theory in research and clinical practice, the measurability of interventions and their effects, the remit of palliative care services, and the tension between generalisation and individual difference. Throughout the process, I tried to maintain the delicate balance between identifying and bracketing my assumptions, biases and personal experiences, and using them to inform and develop the research.

Many of the issues discussed here are relevant not just to palliative care but to healthcare research more generally. At its core, such research aims to be clinically useful; to improve things for patients, families and professionals. All clinical research has limitations which threaten its transferability into practice. Perhaps one thing this thesis as a whole illustrates is the value of different research approaches –

quantitative and qualitative; inductive and theoretically-driven; locally-based and multi-site – in complementing and enhancing the clinical utility of one another.

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Appendix A

Confirmation of UCL Ethical Approval



Professor Nancy Pistrang
Research Department of Clinical, Educational and Health Psychology
UCL

18 January 2012

Dear Professor Pistrang

Notification of Ethical Approval

Ethics Application: 3557/001: Relatives' experiences of end-of-life care

I am pleased to confirm that your study has been approved by the UCL Research Ethics Committee for the duration of the project (i.e. until September 2013).

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events

For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.


Reporting Serious Adverse Events

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research.

Yours sincerely _


Sir John Birch
Chair of the UCL Research Ethics Committee

Cc: Jonathan Totman

UCL Research Ethics Committee, c/o The Graduate School, North Cloisters, Wilkins Building
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Appendix B

Hospice Research and Development Department Approval

Mr Jonathan Totman
Research Department of Clinical, Educational and Health Psychology
University College London
Gower Street
London
WC1E 6BT

4th February 2012

Dear Jonathan

Re: STJ12/003 – Relatives' experiences of end of life care

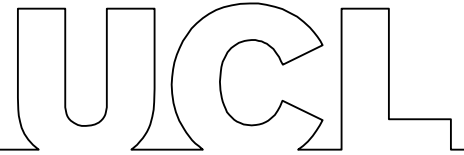
Thank you for submitting your project for consideration to [redacted]. I am pleased to confirm that following governance and organisational reviews, [redacted] has confirmed that they are happy for the study to take place within their organisation as described in the paperwork submitted. Please ensure that you quote the reference and title above when contacting [redacted] regarding this study.

Please ensure that any changes to the study are reported to [redacted] at:
[redacted] for consideration prior to the implementation of these changes including new research staff and changes to the protocol

Yours sincerely

Appendix C

Participant Information Sheet



Relatives' experiences of end-of-life care

Participant Information Sheet

We would like to invite you to take part in this study. Before you decide whether you want to take part, it is important for you to understand what the study involves and why we are doing it. The information below will help you to make your decision. Please ask us if there is anything unclear or you would like more information.

What is the purpose of the study?

This study is being carried out by researchers at UCL in collaboration with XXX Hospice. We would like to find out about relatives' experiences of the final days and weeks of a family member's life. We know that this can be a difficult time and we would like to hear about how it was for you, including the care you and your family member received and how it affected you. We hope that this study will help us to better understand the needs of relatives and improve the quality of care provided by medical and palliative care staff.

Why have I been invited to take part?

You have been invited to take part in this study because you have recently lost a family member who received care from XXX Community Palliative Care Team. We hope that around 12-15 people will take part in the study.

What does taking part involve?

If you choose to participate you will meet with a researcher at XXX Hospice for an interview in which you will be asked about your experiences of your family member's death and the time leading up to it. This will last approximately 45 minutes to one hour. The interview will be audio-recorded so that we do not miss anything important that you say. You will be reimbursed for any travel expenses incurred in coming to the Hospice.

We will also invite you to provide feedback on our analysis of your interview; that is how we understand what you told us. We will send you a written summary of the main themes in your interview and ask for any comments you may have. You do not have to participate in this part of the study if you would prefer not to.

Do I have to take part?

You are free to choose whether or not to take part and to withdraw at any point. Your decision to withdraw will not affect any care you might receive from the Hospice or elsewhere.

What are the risks and benefits of taking part?

Talking about the recent death of a family member can be upsetting, as it may bring up some painful memories. If you find the interview difficult you can take a break or stop altogether. You will not have to answer any questions you do not feel comfortable answering. You will also have a chance to talk with the researcher afterwards about how you found the interview.

You may find some positive aspects to the interview; for some people, talking about and reflecting on their experiences can be a helpful experience. We hope that the information we learn from the study will also be of interest to you, as well as helping improve the care provided to relatives going through similar experiences.

What will happen to the information I provide?

The interview recording will be transcribed to help us analyse the data. The analysis will be carried out by the research team and will identify the main ideas expressed by everyone who participated. The results of the study will be written up as part of a doctoral thesis, which may also be published in a peer-reviewed scientific journal. In addition, we hope that the findings will be useful to inform the care provided for relatives at XXX Hospice.

Will my taking part in this study be kept confidential?

Anything you say during the interview will be kept strictly confidential. All data will be collected and stored in accordance with the Data Protection Act 1998. Audio recordings will be stored on a password-protected computer and will be deleted once transcripts have been made. Names and other personally identifiable information will be removed from transcripts to ensure anonymity. We may include direct quotations from interviews in the published report, but we will not include names of participants and we will make sure that any quotations we use cannot be linked to individuals. We will store the anonymous interview transcripts in a secure location for up to five years.

Contacts

If you have any further questions about this study please contact Jonathan Totman (see contact details below).

Jonathan Totman, Trainee Clinical Psychologist
Professor Nancy Pistrang, Professor of Clinical Psychology
Research Department of Clinical, Educational and Health Psychology, UCL

Telephone:
Email:

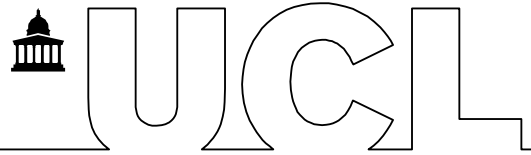
XXX Hospice

Thank you for considering taking part in this study.

This study has been approved by UCL Ethics Committee (Project ID number: 3557/001)

Appendix D

Participant Consent Form



Relatives' experiences of end-of-life care

Participant consent form

Thank you for considering taking part in this study. Please complete this form after you have read the Information Sheet and listened to an explanation of the study. If you have any questions arising from the Information Sheet or the explanation given then please ask the researcher before deciding whether to take part. You will be given a copy of this consent form to keep and refer to at any time.

Participant's Statement

Iagree that:

- I have read the notes written above and the Information Sheet and understand what the study involves.
- I understand that my participation in this study is voluntary and that I am free to withdraw at any point, without giving a reason, and without my care being affected in any way.
- I understand that my interview will be audio-recorded and transcribed and I consent to the use of the recording and transcription for the purpose of the study.
- I understand that the information I give may be used in a published report and I will be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
- I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signed:

Date:

This study has been approved by the UCL Research Ethics Committee (Project ID number: 3557/001)

Appendix E

Semi-structured Interview Schedule

Relatives' experiences of end-of-life care

Interview Schedule

In this study we're interested in finding out about people's experiences of a family member dying at home. I have some questions I'd like to ask you, but mostly I'd like to hear from you about your own personal experiences and what was important for you about this time. I'm very aware this might bring up some strong feelings for you – that's OK with me, but please do take your time and let me know if it becomes too difficult.

1. First of all I'd like to find out a little bit about the time before [family member]'s death.

a) Could you tell me about when you first found out that [family member] was unwell?

Follow-up questions

- Can you tell me about how things were for you at the time?
e.g. living circumstances, work/leisure, relationships
- How did the illness affect [family member] early on?
- How did it affect you?
- What did you think would happen next?

b) How did things change over time?

Follow-up questions

- Were there changes in [family member]'s physical/mental condition?
- Did he/she need caring for? If so, how and by whom?
- Did you have support from any professional services? If so, when and which one(s)?
- When did the palliative care team become involved?
- When did you first think of [family member] as dying?

2. I'd like to move on to think about the last days and weeks before [family member] died. Can you tell me what happened during those last few days?

a) Experiences over the last few days

- Who was there?
- What physical/mental condition was [family member] in?
- What were you doing?
- What were other people doing?
- What do you remember thinking/feeling?
- Did you know what to expect?
- Did anything unexpected happen?
- Could you tell me about anything that you felt went well?
- Could you tell me about anything that you found particularly difficult?
- Can you tell me about when [family member] lost consciousness?
- Can you tell me about the moment when [family member] died?
 - Did you expect it?
 - Did you notice any signs that let you know it was about to happen?
 - Do you have any thoughts about why it happened when it did?

b) Palliative care

- What were nurses/doctors/other health professionals doing?
- Can you tell me about any conversations you had with the nurse/doctor etc?
- Were you involved in any decisions about [family member]'s care?
- How was information communicated to you?
- How were any decisions that were made communicated to you?
- Did you feel you understood what you were being told?
- Was anything that doctors/nurses did particularly helpful or unhelpful?
- Were any drugs given to your [family member]?
 - Do you remember what they were?
 - What are your views on the drugs given to [family member]?
 - What did you understand about their purpose?
 - Do you feel you understood enough about them?

3. Can you tell me about any thoughts you've had about the death of [family member] since it happened?

Follow-up questions

- Have your thoughts or feelings changed at all? If so, how?
- Has your understanding of what happened changed at all? If so, how?
- Looking back, would you have liked anything to be different?
- Is there anything about the way your relative died that still upsets you today?
- Is there anything health professionals could have done differently?

4. Debrief and post-interview questions:

- How are you feeling now?
- How was it talking about [family member]'s death?
- What will you do after this? At times like this it's important to look after yourself.

Signpost participant towards hospice bereavement service

Probe questions (to use at discretion)

- How did that affect you?
- What did you think about that?
- How did you feel?
- What was that like for you?
- What made you feel that way?
- What did you do?
- How did you react?
- How did you manage?
- What were other people doing?
- What was the best/worst thing about that?
- What about that affected you most?
- What did that mean for you?
- What was important about that for you?
- What makes that stand out in your memory?
- Can you tell me more?
- Can you give me an example?

Appendix F

Thematic Analysis Examples

Thematic analysis examples

Table 1 illustrates the stages of the analysis as applied to a transcript extract. Table 2 is an illustrative list of initial, inductively derived codes, organised into a preliminary conceptual framework. Table 3 shows how this framework developed, and the final list of codes included under each theme for the category “responsibility”. As illustrated in these examples, many of the initial code labels were eventually dropped as codes were collapsed and refined as the analysis proceeded. Some of the final theme labels were derived from initial codes (e.g. “finding meaning and solace in caring”, “being the linchpin”). Others were new labels designed to capture common features of multiple codes (e.g. “constantly on the alert”).

Table 1: Example of analysis

Extract	Initial notes	Coding	Theme (Category)
<p>I And you said there were moments that were actually very nice when you were all together. I wonder if you could say a little bit more about those moments?</p> <p>P Yeah just um, just...we'd have the TV on, we'd make something to eat between us, we'd all sit together, watch TV, [sister] would sit up, we'd make her comfortable. It was lovely when we'd changed her bed, changed her pyjamas, brushed her hair, made her all lovely and clean, given her something lovely to eat and we'd sit down to eat and it would just be lovely, all three sisters. It would just be really really nice. And then, you know, knowing that she was really comfortable and happy and secure. Yeah and then she'd go to sleep and then [other sister] would chat and catch up on the day and, you know, then we'd both go and take a sofa each and go off to sleep, it was just really nice, you know sort of like camping out or something when you were kids. It was just like, we haven't been like that together for so many years, we were just really close.</p> <p>I Right, yeah. So there were some things about that caring role that actually felt very positive, to be able to look after her –</p> <p>P Very positive, it just felt, you know, this is what she wanted, and just knowing that she was happy, she was comfortable, every need was met, she was never left, every time she stirred there was somebody there. You know, my girls would come over [other sister] might quickly go over to the shop, chose some food that we thing she</p>	<p><i>Comfort in being able to provide for sister</i></p> <p><i>A deepening of relationships</i></p> <p><i>Welcoming/ embracing the caregiving role.</i></p>	<p><i>Finding meaning and solace in caring</i></p> <p><i>Friends/ family as a source of mutual support</i></p> <p><i>Close to friends/family</i></p> <p><i>Intimacy/ enjoying relationship with patient</i></p>	<p><i>Finding meaning and solace in caring (Meaningfulness)</i></p> <p><i>Intimacy (Isolation)</i></p>

might like, you know just really nice stuff like that, the girls would sit with her, it was just lovely.	<i>Comfort in knowing everything was being done, sister's needs being met.</i>	<i>Finding meaning and solace in caring</i>	<i>Finding meaning and solace in caring (Meaningfulness)</i>
I Yeah, so it was kind of a source of comfort to you to know that you could provide for her.			
P Definitely yeah. And we've got a really strong faith, we're Catholic, so it just felt, it felt right, you know and we felt actually privileged to be able to help somebody in that way, you know.	<i>Caring chimed with values and religious faith</i>	<i>Religious and spiritual meaning</i>	
(...)			
P We didn't know, once we got home, like that first night we came home from the hospital was just...we felt really, I was really...sad, because suddenly when we left the hospital I realised we were on her own. And we'd had good support at the hospital, there was a fantastic nurse there. But um...suddenly you realise you're on your own. But we were told we'd get that support, the same from Macmillan. Yeah, but we didn't.	<i>Loss of support. felt "on our own" - abandoned almost.</i>	<i>Home care – greater risks and responsibilities</i>	<i>Being on my own (Isolation)</i>
I You didn't get it. What do you think you felt you needed at that time, what kind of support would have been helpful?		<i>Responsible by default</i>	<i>Being the linchpin (Responsibility)</i>
P I think sort of moral support, just somebody just sort of you know checking oh this is OK, we're doing this right, you know, you're doing a good job or – not to be praised, but...to be reassured.	<i>Reassurance was needed and lacking.</i>	<i>Being left in the dark</i>	
I Reassurance.			
P Yeah. And to check things out.			

Table 2: Examples of initial codes, organised into a preliminary framework

Codes
Hypervigilance <ul style="list-style-type: none"> • An altered reality • Dread of the worst thing happening • Hard to think clearly • Professionals' actions and interventions loaded with meaning • Looking for clues, checking - physical • Looking for clues, trying to comprehend - psychological
Responsibility <ul style="list-style-type: none"> • An all-consuming job, tunnel-vision • Becoming a medical expert • Being a translator or mediator • Being the fulcrum of care • High sense of responsibility • Home care - greater risks and responsibilities • Relatives' expertise - knowing the patient • Self-scrutiny • Unquestioning assumption of responsibility • Worry about hurting relative • Wrestling with decisions
Doing everything possible to care for relative <ul style="list-style-type: none"> • Concern that relative didn't suffer • Fear of relative being alone - finding ways to be present • Becoming inseparable • Making sacrifices or neglecting self • Protecting relatives, easing existential suffering • Wanting to get it right for relative
Negative experiences of professional care <ul style="list-style-type: none"> • Being dismissed- having to fight to be heard or get needs met • Being left in the dark • Impersonal, insensitive care • Miscommunication • Patient neglected by professionals • Poor coordination of care • Regret or anger relating to professional care
Positive experiences of professional care <ul style="list-style-type: none"> • Timely, proactive and effective patient care • Relative felt looked after • Reassurance and containment • Availability of support - not alone • A personal relationship, humour and warmth

Table 3: Example of codes organised into the final set of themes under the category “Responsibility”

Category: Responsibility	
Theme	Codes included under theme
Being the linchpin	<ul style="list-style-type: none"> • Responsible by default • Being the linchpin • Becoming a medical expert • A shared responsibility (available and proactive)
“You only have one chance to get it right”	<ul style="list-style-type: none"> • Wanting to get it right for relative, do everything possible • Relatives' expertise knowing the patient.
Constantly on the alert	<ul style="list-style-type: none"> • Making sacrifices or neglecting self • Looking for clues as to relative's condition • Dread of the worst thing happening • An all-consuming job
“Am I doing enough?”	<ul style="list-style-type: none"> • Wrestling with decisions • Self-scrutiny and guilt

Appendix G

Feedback invitation letter

Dear

A little while ago you took part in a research interview in which you spoke about your experiences of end-of-life care. You may remember me mentioning at this time that I would be writing to you as part of the process of identifying the key themes across all the interviews.

Enclosed is a summary of what I think were the main themes of your interview. I would like to invite you to provide feedback on this summary, including its accuracy and the extent to which it captures the things that were important to you about this time. Please feel free to comment on any aspect of the summary and to point out anything I may have missed.

Please know that you do not have to take part in this aspect of the research if you would prefer not to. If you would like to, please write your comments on the feedback sheet enclosed and return it in the envelope provided. Alternatively, you can email me at XXX or telephone on XXX.

Thank you very much again for kindly contributing to my research.

Yours Sincerely,

Jonathan Totman

Participant feedback sheet

Participant ID:

1. To what extent do the themes in the summary accurately reflect your experiences?

2. Is there anything that has been missed out that you would like to add?

3. Any other comments