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RESEARCH METHODOLOGY: INSTRUMENT DEVELOPMENT

Gaining consensus on family carer needs when caring for someone dying at home to develop the Carers' Alert Thermometer (CAT): a modified Delphi study

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Abstract

Aim. To report a multi-phase modified Delphi study conducted with carers and professionals to identify the priority areas for inclusion in an alert screening tool for carers providing support to someone dying at home.

Background. Internationally, there is a growing emphasis on increasing choice for patients who wish to die at home which relies heavily on care provided by the unpaid family carers. Family carers can have high levels of unmet needs comprising their psychological and physical health and their ability to provide effective care and support. Development of an alert tool to identify carers' needs in everyday practice required identification and consensus of the priority areas of need for inclusion.

Design. Multi-phase modified Delphi study and instrument development.

Method. Qualitative and quantitative data collection took place between 2011–2013 with 111 carers and 93 professionals to identify carers' needs and gain consensus on the priority areas for inclusion in the alert tool. An expert panel stage and final evidence review post-Delphi were used.

Results. The Delphi panels had high levels of agreement and consensus. Ten areas of carer need across two themes of 'the current caring situation' and 'the carer's own health and well-being' were prioritized for inclusion in the alert tool. An optional end-of-life planning question was included following the final stages.

Conclusions. The results provide evidence of carers' needs to be assessed, areas for consideration in the education of those who support carers and someone dying at home and targeting of services, while demonstrating the usefulness and adaptability of the Delphi method.

Keywords: caregivers, carers, Delphi, end-of-life care, expert panel, home care, needs assessment, nursing, palliative care

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Why is this research or review needed?

- The daily end-of-life care for people who choose to die at home can place a high demand on family carers.
- To enable assessment of carers' needs to become embedded in practice there is a need for a tool which is short and focused on the key priorities to make it practical for everyday practice.
- No consensus study involving both carers and professionals to identify the prioritized carer needs was identified in literature, so a mixed-method, multi-phased Delphi was conducted to gather this evidence.

What are the key findings?

- There was a high level of agreement and consensus between the Delphi panels on the prioritized carer needs to be included in the alert tool across two main themes of 'the current caring situation' and 'the carer's own health and well-being'.
- End-of-life planning was the lowest ranked domain by both panels in all stages of the Delphi demonstrating the priority given to identifying needs and supporting carers in their current caring role rather than looking ahead.
- The pragmatic approach taken to modify the Delphi, whilst maintaining a clear focus and criteria for each round, demonstrates the usefulness and adaptability of the Delphi method and value of an expert panel stage.

How should the findings be used to influence policy/practice/research/education?

- The prioritized areas from the Delphi provide evidence of the areas to be included in the assessment of carers, targeting of services and training of staff from the perspectives of carers and professionals.
- The low ranking of the end-of-life domain suggests that prioritizing sensitive conversations around end-of-life planning can be challenging for professionals and carers when the focus is on everyday caring.
- The Carers' Alert Thermometer (CAT) developed from the prioritized areas is an evidence-based, easy to use tool to identify carer needs and facilitate discussions with carers.

Introduction

Internationally there has been an increase in policies supporting patients to die in their place of choice (e.g. Health

Canada 2007, Department of Health 2008, 2014, Commonwealth of Australia 2010). To support these initiatives, countries have implemented various interventions including services which support end-of-life care at home (Leadbeater & Garber 2010, Gott *et al.* 2013, Jack *et al.* 2014). However, the number of hospital deaths remains high accounting for approximately 50% of deaths globally, although there is wide variation across countries (Broad *et al.* 2013). In the UK, there is gradual improvement in the number of home deaths increasing from 20.6–23.5% between 2004–2010 (Gomes *et al.* 2012). Despite this trend barriers to home deaths still exist, including the availability and responsiveness of services to support carers and patients who are dying at home which can vary considerably (Social Care Institute for Excellence (SCIE) 2013).

Background

Caring for people who choose to die at home falls primarily to unpaid carers who comprise family members or friends. The National Council for Palliative Care (NCPC) defines carers as 'people who provide unpaid support to a family member or friend' (NCPC 2012 p. 5). In the UK, there are approximately 6.5 million people providing unpaid care to another person due to a physical or mental health condition (NCPC 2012). It is estimated that half a million carers are providing end-of-life care to someone at home (NHS England 2014). The actual number of carers may be much higher due to the number of 'hidden carers' who are not recognized by health or social services, or, indeed, not recognized by themselves as being carers (Carduff *et al.* 2014). Societal changes and geographical mobility have led to families being more widely dispersed which can result in carers coming from a range of relationships with the patient and not necessarily the traditional next-of-kin. Where carers are not immediate family, they are at additional risk of being part of an 'invisible network' who are not recognized by services and may not receive the support required (Burns *et al.* 2013, Carduff *et al.* 2014).

In addition to providing care to someone at home, many carers have other caring responsibilities for children or grandchildren (Leadbeater & Garber 2010, Payne & Morbey 2013). Due to the ageing population there is an increase in the number of older carers who are often frail and have their own health conditions to manage (Office for National Statistics (ONS) 2013, Carduff *et al.* 2014). As people approach the end-of-life, those who care for them can incur increasing needs putting them at risk of physical strain and psychological distress; affecting their ability to care and their own health and well-being. Providing

physical care, which can involve heavy lifting and complicated medication regimes, along with lack of sleep can lead to increasing fatigue (Funk *et al.* 2010, Stajduhar *et al.* 2010). Carers can also become socially isolated and removed from their normal lives, with additional challenges such as travelling to provide care (Social Care Institute for Excellence (SCIE) 2013). Furthermore, there are often financial consequences with potential loss of earnings or reduced employability as their caring role increases (Gardiner *et al.* 2014). Research in several countries has highlighted the need for identification of carers and their needs assessed on a regular basis to ensure appropriate support is provided and prevent potential hospital admissions for the patient, due to the carer being unable to cope (Jack & O'Brien 2010, Gott *et al.* 2013, Gardiner *et al.* 2014).

Internationally, there is recognition of the need to support the end-of-life carers; including the 2014 European Declaration on Palliative Care (2014) and the World Health Organisation (WHO) definition of palliative care which include the importance of providing support to address the needs of the family and carers (WHO 2010). Many countries have a strong policy commitment to supporting carers of people approaching end-of-life including the UK (Department of Health 2008, 2014), Canada (Health Canada 2007) and Australia (Commonwealth of Australia 2010).

Current UK policies and strategies for end-of-life care include support for carers by engaging with them and offering holistic, comprehensive assessments to support their current and changing needs and preferences (National Institute for Health and Clinical Excellence (NICE) 2011, NHS England 2014). The Leadership Alliance for the Care of Dying People report (Department of Health 2014) outlined five priorities for end-of-life care. Priority four states that 'The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible' (p 87).

A systematic review found no evidence-based tools suitable for use in everyday practice to assess the needs of carers providing end-of-life care at home; those available tend to be specific to services or lengthy research tools (Hudson *et al.* 2010). Any assessment tool to identify needs of carers providing end-of-life care at home also needs to be appropriate for staff most likely to administer it. Many people receiving end-of-life care at home in the UK are cared for by community health and social care teams, with limited support or no input from specialist palliative care teams (Ahmed *et al.* 2004). Private care agencies that provide healthcare assistants (non-registered support staff) is also becoming more prevalent with non-specialist staff having most contact with carers supporting people dying at home.

Given increasing demands on community health and private agency staff, coupled with financial implications of time spent on lengthy assessments, it is necessary for any screening tool to be easy to administer, short and most importantly, include priority areas to be assessed on a regular basis with carers. Although much is available internationally about the needs of carers from the carer or professional perspective, no consensus studies have been identified which explore the prioritizing of carer needs whilst providing end-of-life care from both of these perspectives. A Delphi approach was chosen to gain agreement from carers and professionals on a prioritized list of carer needs to inform the development of an alert tool to regularly assess needs of carers, whilst meeting pragmatic requirements for using it in practice. The Delphi approach has been used with professionals and carers to gain consensus on priorities in other areas of health care such as cancer care services (Efsthathiou *et al.* 2011). This paper presents a detailed description of the modified Delphi process used to create the Carers' Alert Thermometer tool (CAT), along with consideration of modifications needed and value of an additional expert panel stage.

The study

Aims

The aims of the study were to conduct a multi-phase modified Delphi with carers, health and social care professionals and an expert panel, to reach consensus on the priority areas for inclusion in a short screening instrument of carers' needs.

Methods

A modified Delphi design, using qualitative and quantitative data sequentially through five phases, was used to identify the key carer needs from the perspectives of carers and professionals to develop the CAT. The study ran from April 2011–August 2014; the data reported here were collected between October 2011–September 2013. Data collection methods and sample sizes for each phase are displayed in Figure 1. The Delphi technique was chosen as a proven method to gain group consensus from participants, who are knowledgeable of the topic, through successive rounds (McKenna 1994). The Delphi method has been widely used in health care research to identify priorities for development of services, guidance and tools (e.g. Langlands *et al.* 2008, Malcolm *et al.* 2009, Keeney 2010).

There are challenges implicit in the pure Delphi method which regularly leads to it being adapted by researchers, to

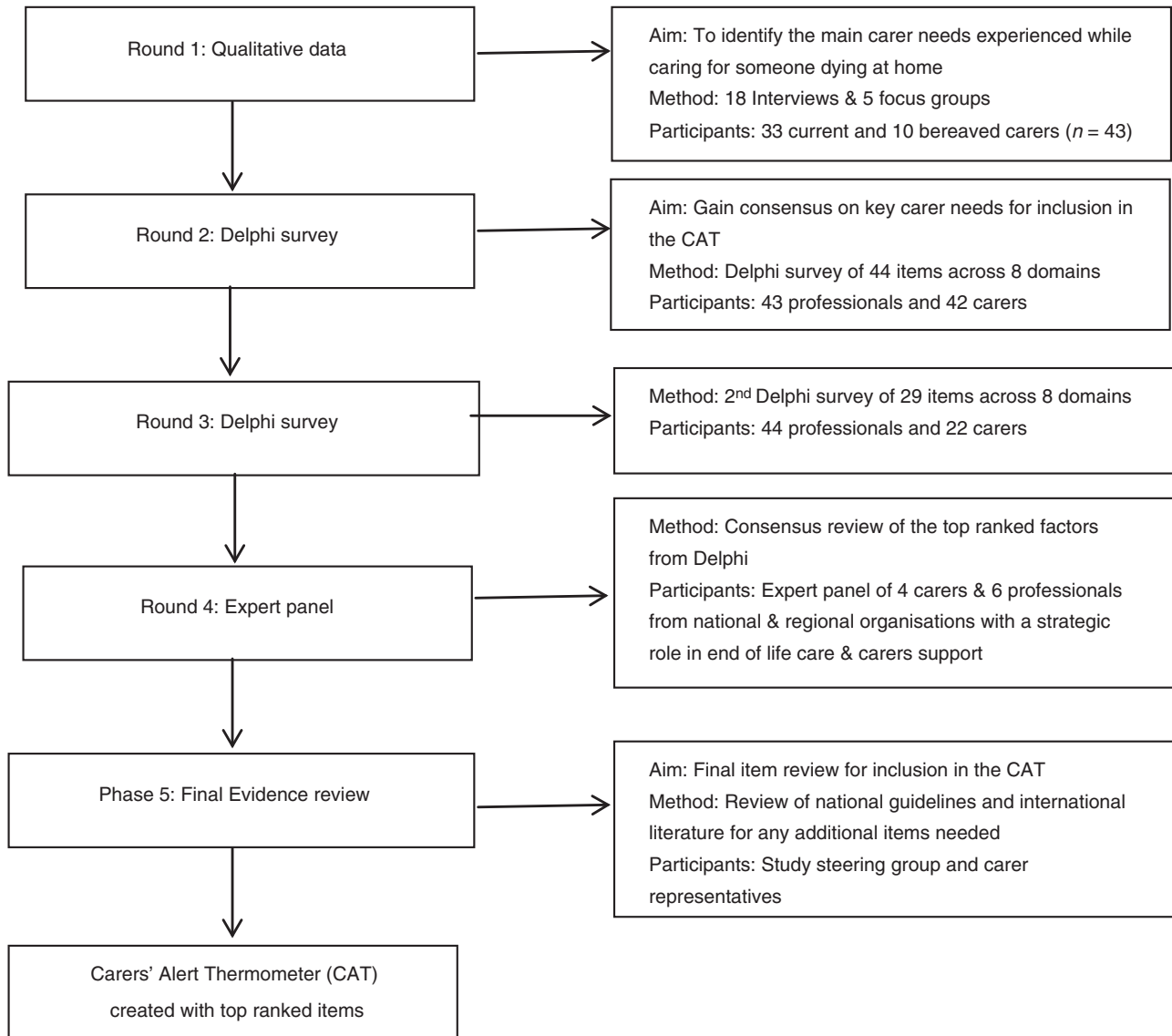


Figure 1 Flowchart of the multi-phase modified Delphi.

fit the needs of the study (Keeney *et al.* 2006). A critique of Delphi studies identified despite the popularity of the method, there is no general standard of how to measure consensus. Researchers often adapt the method and analysis to achieve their study aims, without giving sufficient attention to group stability or pre-determining the criteria for consensus (Von der Gracht 2012). It is the responsibility of researchers to ensure transparency about the methods used, any pragmatic modifications required and limitations they may bring to the study being clearly reported (Keeney *et al.* 2006).

Each round of the modified Delphi in this study had an explicit focus, with pre-determined criteria for consensus and any adaptations were based on findings of the previous round.

In the Delphi rounds the views of the carer and professional panels were treated equally, to gain consensus from both perspectives on the key areas to include in the CAT.

When using the Delphi method to identify priorities for guidelines or clinical interventions, some studies have incorporated an additional stage for review by an expert panel or professional body, to ensure the final product or guidance is endorsed or is fit for purpose (Hermans & Cutting 2013, Yazdany *et al.* 2013). As the proposed CAT tool needed to be suitable for practice it was essential that national guidance on end-of-life care support, (including that for carers) and any new literature published during the study were reviewed and incorporated into the final tool. To meet these objectives, the modified design included an

expert panel review of the Delphi results and an additional final evidence review stage.

Participants

A purposive sampling strategy was used to recruit participants, to each stage of the study, who were either current or bereaved carers, or professionals with experience of supporting carers to each phase of the study (Patton 2002). The contribution of young carers in supporting parents and grandparents at the end of their lives is acknowledged (Gandy *et al.* 2012), but their specialist requirements (not least educational) were outside the scope and purpose of the CAT and for this reason they were excluded from the current study. The inclusion criteria required all participants to be aged 18 years or over and able to give consent to take part in the study. Experience of participants was essential to ensure they could offer a wide range of perspectives on the key needs affecting carers providing end-of-life care to someone dying at home. Efforts to engage with carers who represented the regional population in terms of geography, sex, race and social economic status were made by recruiting from a wide range of health, social care and voluntary services.

Participants groups were:

- 1) Carers who were: (i) current carers providing end-of-life care to someone at home; or (ii) bereaved carers who had previously had a caring role for someone;
- 2) Professionals who had experience of supporting patients and/or carers providing end-of-life care including representatives from health, social care, education, charities, Carer Centres, NHS (Primary, Community and Hospital Trusts), Local Authority, Social Services;
- 3) Professionals with a strategic role in end-of-life care and carer support with regional and national organizations.

Instrument

The data collection and results of each phase of the Delphi are presented together in the analysis section due to the iterative nature of the study. A summary of methods and participants for each phase of the study is presented in Figure 1. The resultant Carers' Alert Thermometer is a short alert tool of 11 questions, suggestions of appropriate actions for each alert and an action plan to be jointly completed by the carer and the assessor.

Ethical considerations

Ethics approval was granted for all stages of the study by the University and local Research Ethics Committees.

Data analysis

All qualitative data and open comment text gathered during the study were analysed using a thematic analysis approach (Braun & Clark 2006). Data were analysed independently by two members of the research team to develop and refine the emerging themes and introduce rigour into the analytic process. Quantitative data gathered from the Delphi and expert panels were entered into IBM SPSS Statistics for Windows (Version 20.0; IBM Corp., Armonk, NY, USA) for analysis. Measures of central tendency and level of dispersion are often used in Delphi studies to present the participant responses of the participants (Hasson *et al.* 2000). Median and mode are typically used, but use of the mean is also possible (Murray & Jarman 1987). In this study descriptive statistics were used to explore mean, median and standard deviations for individual items and ranking of domains, for the professional, carer panels and total sample (Hasson *et al.* 2000).

Criteria used to define and determine consensus in a Delphi study is subject to interpretation, with studies reporting variations, dependent on the sample numbers and aim of the research (Hasson *et al.* 2000, Keeney *et al.* 2006). However, the importance of an agreed criterion for consensus and transparency is vital (Keeney *et al.* 2006, Von der Gracht 2012). On completion of each round in the study, percentages for individual items were analysed for the carer and professional panels and total sample. The following pre-determined consensus criteria were used:

Criterion to accept an item: at least 70% of the carer and professional panels rated an item as (4) 'important' or (5) 'extremely important'

Criterion for re-rating an item: if 70% of one panel or the total sample rated an item as (4) 'important' or (5) 'extremely important' but the other panel did not, suggesting disagreement between the panels.

Criterion for rejecting an item: any items that did not meet the 70% criteria in either panel or the total sample.

Results

Round 1

Round 1 used interviews and focus groups to gather qualitative data to identify key carer needs. This approach was employed to ensure that prospective data from current carers could be gathered ($N = 33$), along with retrospective data from bereaved carers ($n = 10$), to identify a range of different needs along the caring trajectory. A sample of 43 carers were recruited through general practitioners (GPs), voluntary carer organizations, support groups, adult hos-

pices and the use of local media including the study website. Age range of participants was 20-80 years old (Table 1). All participants received an information pack and provided written consent, prior to data collection.

Eighteen interviews and five focus groups were conducted with 43 carers, to identify the key needs of carers when providing care to someone dying at home. Interviews were mainly conducted in the carer's home, with two conducted at an adult hospice. Focus groups took place at carer centres and two adult hospices. A semi-structured guide was used for direct data collection of: demographic information, carers' perception of being a carer, their experience of being a carer, any support or assessments they had received and their views on the proposed screening instrument being developed by the study. Interviews and focus groups were digitally recorded and transcribed verbatim.

An abundance of carer needs were identified from the qualitative data, using a thematic analysis approach (Braun & Clark 2006). Themes identified were supported by existing literature and fell into two overarching themes of support needed by the carers to provide care in 'the current caring situation' and support needed for the 'carer's own health and well-being'. The final list of themes and items with descriptions and examples from the data were reviewed by the study steering group and carer representatives to finalize the items for the Delphi.

Round 2

The themed items identified as carer needs in Round 1 were developed into a Delphi survey for distribution to carers

Table 1 Phase 1 participant characteristics ($n = 43$).

| | N |
|--|----------|
| Gender | |
| Female | 26 (60%) |
| Male | 17 (40%) |
| Primary diagnosis of person being cared for | |
| Cancer | 14 (33%) |
| Neurodegenerative diseases | 13 (30%) |
| Respiratory diseases | 10 (23%) |
| Stroke | 2 (5%) |
| Aging (multi-organ failure) | 2 (5%) |
| Auto-immune diseases | 1 (2%) |
| Mental Health | 1 (2%) |
| Relationship of person receiving care from the carer | |
| Spouse | 27 (64%) |
| Parent | 13 (30%) |
| Sister | 1 (2%) |
| Son | 1 (2%) |
| Friend | 1 (2%) |

and professionals, to rate their importance for inclusion in the CAT. A comprehensive approach was taken to ensure the survey included all key needs identified by carers resulting in 44 items across 8 domains (Table 2). In Section A of the survey, participants were asked to rate all items 'How important do you think each item is for inclusion in the CAT?' on a 5-point Likert scale of importance from 1 being 'not at all important' to 5 being 'extremely important' for all items. Each domain also had a section to provide comments. Section B asked participants to rank the eight domains from 1 to 8. Section C gathered demographic data from participants.

With the advancement of the Internet, the use of e-Delphi has become very popular as method of online data collection (Cole *et al.* 2013). SurveyMonkey® (www.surveymonkey.com) was used to create an online Delphi survey, along with a paper version. Invitations were sent to a purposive sample of professionals, to capture views from a range of staff that have contact with patients and carers. Professionals and national organizations were asked to cascade the email invitation to other appropriate professionals and organizations. Information fliers about the study and paper copies of the survey were distributed to carer centres and adult hospices across the North West of England.

Round 2 – Results

The Round 2 survey was completed by 43 professionals and 42 carers ($n = 85$). Thirteen carers completed paper copies, all other responses were completed online. There was a very high level of rating and consensus on the individual items resulting in 34 of the 44 items meeting the pre-determined acceptance criteria. As the aim of the Delphi was to gain consensus on the key needs, for a short, manageable tool, the study steering group agreed to amend the first criterion to accept an item only if it had a total sample median of (5) 'extremely important'. More stringent criterion resulted in 24 items being included, 15 items were excluded and five items were included for re-rating due to disagreement, resulting in 29 items for Round 3 (Table 2).

Round 3

Due to high level of rating in Round 2 and the need to prioritize items for inclusion in the CAT, the format of the survey was changed for Round 3. In Section A, the number of items in each domain ranged from 2 to 6 items. Given the lower number of items in each domain, participants were asked to rank the items in each domain from the most important (1) to the least important. In Section B

Table 2 Number of items per domain in the Delphi rounds.

| Domain | Descriptor | Number of items in R2 | Number of items in R3 | Number of ranked items in R4 |
|---|--|-----------------------|-----------------------|------------------------------|
| 1. Understanding the current caring context | Questions to assess the carer's 'lived situation' e.g. who they were caring for, other demands on their time, caring responsibilities, their understanding of the diagnosis and prognosis of the person they were caring for | 10 | 5 | 2 |
| 2. Current care provided by the carer | Questions to assess the different levels of care provided e.g. physical, emotional and practical care | 4 | 2 | 2 |
| 3. Carer's relationship with professionals | Questions to assess the carer's view of their relationships with professionals providing care to the person they cared for | 4 | 4 | 2 |
| 4. Respite and emergency care support | Questions to assess the carer's need for a break or respite care and what would happen in an emergency or if they were unable to provide care | 3 | 3 | 1 |
| 5. Financial support and assessments | Questions to assess the carer's financial issues and any assessments received | 7 | 5 | 1 |
| 6. Carer's own health and well-being | Questions to assess the carer's own needs and the balancing of their own health needs with demands of caring | 6 | 4 | 1 |
| 7. Support for the carer | Questions to assess the carer's support network, use and awareness of services | 6 | 2 | 1 |
| 8. End of Life (EoL) Care and planning | Questions to assess the carer's awareness of EoLC wishes and documentation, and bereavement support | 4 | 3 | 0 |

participants were presented with the total sample group response from Round 2 for the domain ranking and asked to rank the domains a second time. Any participants who had not completed the previous round were asked to complete the Section C demographics.

Round 3 – Results

The Round 3 survey was completed by 44 professionals and 22 carers ($n = 66$). Eleven carers completed paper copies, all other responses were completed online. There was a high level of agreement within and between the panels. Both panels ranked the same item as the (1) 'most important' in seven of the eight domains. The only domain with disagreement was the end-of-life planning domain, where carers ranked 'awareness of bereavement support' highest and professionals ranked 'knowing the wishes of the patient and completing the appropriate documentation' highest. When ranking the eight domains for a second time both panels confirmed their ranking of understanding the 'current caring situation' and 'carer's health and well-being' as the most important domains with 'end-of-life care and planning' and 'financial support' as the least important (Table 3). The top two ranked items for each domain resulted in 16 items for Round 4, which included the two items where there was disagreement in the end-of-life domain between the panels.

Round 4 Expert Panel

An expert review panel comprising four carers who participated in earlier stages of the study and six professionals, with a strategic role in national or regional organizations (for end-of-life care or carer support) were sent the findings of the Delphi by email and asked to review them in a two-step process. In Step 1 the panel were asked to review and comment on the 16 items, or raise any important issues they felt were missing. In Step 2 the panel ranked items from 1-10 for inclusion in the CAT, excluding the other items. The panel returned their completed forms electronically.

Round 4 – Results

The open text comments were analysed using the same process as Round 1 (Braun & Clark 2006). The panel commented that the items were very inclusive of carer needs:

I feel that this is a comprehensive list of the issues that are important to carers (Professional, R4 panel).

Panel members also suggested that, depending on the individual circumstances, all items could be viewed as important making the prioritizing of items a challenge:

I found this quite hard to choose a top ten because if an important element of the support is missing it has a domino effect on the quality of support the carer can give the patient (Carer, R4 panel).

Table 3 Ranking of domains by panels in Round 2 and 3.

| Domain | Round 2 Ranking | Round 3 Ranking |
|---|-----------------|-----------------|
| Domain 1 Understanding the current caring situation | 1st | 1st |
| Domain 2 Current care provided by the carer | 4th | 4th |
| Domain 3 Carer's relationship with professionals | 5th | 5th |
| Domain 4 Respite and emergency care needs | 6th | 6th |
| Domain 5 Financial support and assessments | 7th | 7th |
| Domain 6 The carer's health and well-being | 2nd | 2nd |
| Domain 7 Support for the carer | 3rd | 3rd |
| Domain 8 End of life care and planning | 8th | 8th |

The analysis process used the same pre-determined criteria as previous rounds to explore the rankings of the expert panel. Although there was some spread in the responses, there was good agreement in the panel of the top 10 items (Table 2). The top ten items included at least one item from seven of the eight domains. Although some panel members had included items from the end-of-life care planning domain in their rankings, there was no consensus reached for inclusion of these items by the expert panel. The end-of-life care planning items were rated 15th and 16th of the 16 items. Across the four rounds, 10 items to identify the main carer needs of those providing the end-of-life care to someone at home were noted by the carers and professionals (Table 4).

Final evidence review

Prior to finalizing the CAT from the items ranked by the Delphi and expert panel as those with the highest priority for inclusion, a final evidence review of national UK guidelines and international literature was conducted to ensure that the CAT would be consistent with any developments or new evidence that were published during the data collection of the project. Due to the importance of end-of-life planning in the current international guidance for palliative and end-of-life care, the steering group agreed to include the highest rated item from the end-of-life planning domain, as an optional question in the CAT for the pilot. The 11 items can be seen in Table 4 in ranked order.

The 11 items were developed into questions to identify carer needs in the CAT along with a scoring system and

suggested next steps for any alerts identified. The CAT was piloted and went through several consultations exercises with carers and professionals to finalize the question structure and number and scoring system. The details of the evaluation and implications for practice are published elsewhere (Knighting *et al.* 2015). In September 2014, the finalized CAT was publically launched and it can be freely accessed at the study website for use on a not-for-profit basis (www.edgehill.ac.uk/carers).

Discussion

The Delphi findings present a consensus view from carers and professionals on the needs which can present the most challenges to carers, whilst providing care to someone dying at home. Despite the range of roles and perspectives of the panel members, there was a high level of agreement and consensus on the key items to be included in the CAT.

Key needs identified during the study were encompassed in two predominant themes of support for the carer. The themes were related to support for the carer to provide the care needed to the person dying at home and the support carers need to manage their own health and well-being. These overarching themes mirror the literature about the different roles that carers have when providing care and the support they may need (Ewing & Grande 2012). Importance of these themes was also reflected in the ranking of the eight domains by both panels in Round 2 and 3. The panels ranked the 'current caring situation' and 'carer's health and well-being' as the priority domains in both rounds, reflecting their view that any assessments should prioritize these aspects of the carer's experience.

Key items ranked for inclusion in the CAT in the current caring situation theme were related to understanding the diagnosis and care needs of the person being cared for, awareness of emergency support and if the carer requires any legal advice. Key items ranked for inclusion in the carer's own health and well-being theme, were associated with the carer's relationship with professionals and direct support for themselves, including financial issues and breaks from caring. The importance of these items is reflected in the literature, as carers tend not to regard themselves as a carer or consider their own needs (Carduff *et al.* 2014). Carers often ignore their own personal and health needs to concentrate on providing the best care possible to others (Harding & Higginson 2001, Carduff *et al.* 2014). Carers can also face financial hardship, due to loss of income or inability to continue employment whilst providing care leading to stress and potential breakdown in their ability to

Table 4 Final ranked items for inclusion in the CAT following expert panel by theme ($n = 10$).

| Items 'How important do you think each item is for inclusion in the CAT?' | Consensus ranking | Mean (SD)* |
|---|-------------------|-------------|
| Theme 1: Current Caring Situation (4 items) | | |
| ...if the carer understands the expected progress of the condition of the person they are caring for? | 1 | 2.88 (2.64) |
| ... if the carer feels able to support the psychological/emotional needs of the person they care for? | 2 | 3.25 (3.86) |
| ... if the carer has a named person or number to call in an emergency or with any concerns about the person they care for? | 6 | 4.50 (2.98) |
| ... if the carer has responsibility for making decisions about the care of the person they care for, due to their condition or mental capacity? | 7 | 5.20 (3.27) |
| Theme 2: Carer's Health and Well-Being (6 items) | | |
| ... if the carer feels that professionals involve them in decision making by seeking their knowledge and expertise about the care needed by the person they care for? | 3 | 3.88 (1.55) |
| ... if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break? (if services available) | 4 | 4.00 (2.12) |
| ... if the carer feels they are receiving the support they need from professionals at the time they need it? | 5 | 4.13 (2.17) |
| ... if the carer knows of and has applied for all appropriate funding, such as benefits, mobility schemes? | 8 | 5.86 (1.86) |
| ... if the carer feels they are currently receiving enough support? | 9 | 6.00 (3.35) |
| ... if the carer is able to balance their own health needs with the demands of caring? | 10 | 6.11 (3.41) |
| End of life care planning (optional question) | | |
| ... if the carer knows the wishes and preferences of the person they care for, and they have been written down and shared, e.g. advance care planning (ACP) document? | Not ranked | 8.43 (1.13) |

*Items were ranked from (1) 'most important' so the most important item has the lowest mean.

continue providing care (Gott *et al.* 2013, Gardiner *et al.* 2014).

An interesting finding of the panels was the low ranking of the end-of-life planning domain. When looking at item level in the panels, it is not unexpected that carers would rate an item about bereavement support most highly and professionals rate knowing the patient's wishes and having the appropriate documentation completed as the most important item. However, planning for the final stage of a patient's care is a key component in end-of-life care, it might be expected that this domain would rank higher for care provided within the last 12 months of life. This low ranking may be indicative of the panels focusing on 'the here and now situation' of caring, rather than looking into needs of the future. However, good quality end-of-life care requires planning and time needed to have sensitive conversations with patients and families, with the recording of agreed decisions (Department of Health 2008, 2014).

Another view could be that the panels' rankings suggest that conversations about death and planning end of life are still challenging and remain taboo. With the increase in globalization and migration there are many social, cultural, spiritual and religious factors which impact on understand-

ing and discussions of end-of-life care and bereavement support available to families. A study of culture in end-of-life care across seven European countries found evidence of 'clearly distinguishable national cultures of end-of-life care, with differences in meaning, priorities and expertise in each country' (Gysels *et al.* 2012). This diversity is reflected in other countries across the world, where there is wide variety in types of palliative care services and expertise available. Understanding the meaning of illness and any socio-cultural beliefs about preparing for death is an important factor which will influence the priority given to end-of-life planning by patients and carers. Influence of these factors should also guide professionals' decisions when introducing conversations about end-of-life care for each patient and their family (Blackhall *et al.* 1995, Tellez-Giron 2007)

Socio-cultural context of family can impact on involvement of carers and timing of planning for end-of-life care. Awareness of these issues can ensure that carers are identified and their needs supported in a timely and sensitive manner. As end-of-life care planning is prioritized in the UK guidance and the international literature it was determined that it would be included as an item for assessment in the CAT.

Strengths and limitations

A main strength is the involvement of carer representatives throughout the process of the study, from informing design to interpreting findings. The study also reports on priorities for assessment of carers' needs identified by consensus of both carers and professionals and as such findings support and extend the existing international literature on carers' needs. Study participants were mainly from the North West of England, which may limit generalizability of the findings. However, concordance of the findings with international literature and national representation from professionals in the expert panel does strengthen them and their relevance to wider audiences.

Some pragmatic decisions were made about the study design during the course of the study. Due to participants including carers for people who were dying at home and busy professionals, the time required to complete the Delphi survey and number of rounds had to be seriously considered to avoid participant burden. In consultation with carer and professional representatives of the steering group, it was agreed that one qualitative round and two survey rounds would be most acceptable and typical of many reported Delphi studies.

The high-importance rating for 34 of the 44 items in Round 2, along with the comments from participants that 'all items were important', indicated that the high rating response would likely be repeated in Round 3. As the Delphi was to identify priority items for questions in the CAT, two changes were made to the design in consultation with carer representatives and the steering group; inclusion criteria for Round 2 responses became more stringent and a ranking only response was introduced for remaining items in Round 3. The use of a ranking only process in Round 3 without a dual rating process enabled participants to provide a clear prioritization of items whilst avoiding an increased time burden on participants. This departure from a typical Delphi approach of rating items in multiple rounds, with or without ranking, meant that no analysis could be conducted to assess rating change between the two rounds, as different data were collected. However, the ranking process met the aim of the study by facilitating clear prioritization of the top items for inclusion in the CAT and agreement analysis was performed for each round between the panels and as a total sample using the pre-determined criteria.

The study took place in 2011–2014 but the data collection reported in this paper took place during the first two years. The final year focused on additional consultations with carers and professional after the pilot to refine the

CAT and supporting guidance to ensure it was fit for practice and consistent with current policy and practice prior to its public launch in September 2014.

Conclusions

This study identified a consensus of the priority items of carer needs from both carer and professional perspectives to be included in the CAT alert tool. Concordance of the priority items chosen by the Delphi and expert panels with the international literature provides good evidence to support targeting of services and areas to be included in the assessment of carers. The lower priority given to end-of-life planning suggests the importance attached to the active caring role and not wanting to look too far ahead. The low ranking may also be indicative that having these sensitive conversations can still be challenging, both for professionals and the patient and family. During the pilot the CAT was reported to be a short and easy to use tool to identify carer needs and facilitate such discussions (Knighting *et al.* 2015). The CAT has subsequently been implemented by several NHS and charity organizations enabling further evaluation of its feasibility in practice, training needs for staff and the longitudinal impact on carer support and well-being.

Throughout, the study team followed guidance to ensure that each round had a clear focus and criteria, transparency about the process and reported pragmatic modifications made to meet the aims of the study. Modifications made to the Delphi design by adding an expert panel review and additional evidence review, along with the change of participant response required between Round 2 and 3 enabled the aims of the study to be met, demonstrating the usefulness and adaptability of the Delphi method and importance of pre-determined aims and criteria for all stages.

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Conflict of interest

No conflict of interest has been declared by the authors in relation to the study itself. Note that Brenda Roe is a JAN editor but, consistent with usual practice, this paper was subject to double blind peer review and was handled by another JAN editor.

Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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