

## **Family carers' experiences of coping with the deaths of adults in home settings: a narrative analysis of carers' *relevant background worries* (RBW)**

### **Abstract**

**Background.** Internationally, evidence on the support needs of family carers who look after a terminally ill adult in home settings is incomplete.

**Aim.** To illustrate the relevance of 'relevant background worries' (RBW) in family carers' accounts of caring at home for a dying adult.

**Design.** A qualitative cross-sectional observational study was conducted in England, UK, in 2011-13 on the experiences of adult family carers (n=59) of older dying adults (aged 50+) with malignant and/or non-malignant conditions. Interviews occurred post-bereavement. This paper reports on a sub-set of participants' interview transcripts (n=30) where narrative analysis was undertaken.

**Setting/participants.** Carers were interviewed in their home setting, having been purposively recruited via GP practices in two study sites in England. The sub-set of participants (n=30) was purposively selected from the parent sample with reference to: carers' age, relationship to the patient, family circumstances, study sites.

**Results.** Evidence is provided on the importance of what we conceptualise as carers' 'relevant background worries' (RBW); these varied in nature, significance and impact. Four case-studies are presented where these worries constituted psycho-social factors that impacted on caregivers' actions and emotional wellbeing. Two themes are discussed: i) whether relevant background worries are important enough to be identified and responded to, ii) how such worries could be picked-up and managed by professionals.

Conclusion. It is argued that the quality of clinical practice could be improved if specialist palliative care teams in community contexts both identified and responded to significant support needs associated with family carers' relevant background worries.

**Key words:** palliative care; end-of-life care; family caregiving; narrative methods; narrative analysis; home deaths.

**What is already known about this topic?**

- Despite much research, there is insufficient evidence on the support needs of family carers who care for adult patients who are dying in home settings.
- International trends in place of death mean that family carers will be increasingly relied upon to deliver care to dying people in home settings.
- Both policy makers and researchers encourage new research on this topic.

**What this paper adds?**

- This paper provides new evidence on caregivers' support needs by analysing interview data using narrative methods.
- A new concept is introduced: the 'relevant background worries' (RBW) of family carers.
- Four case-studies illustrate the variability of family carers' relevant background worries.
- Relevant background worries vary in nature and significance, but may constitute psycho-social factors that impact on caregivers' actions and emotional wellbeing.

**Implications for practice, theory or policy**

- The quality of clinical practice could be improved if specialist palliative care teams both identified and responded to the support needs associated with significant relevant background worries amongst family carers.
- It is recognised that identifying and responding to caregivers' relevant background worries demands additional resources, so suggestions are made about how such worries could be identified and managed by professionals.

## 1. Introduction

What are the support needs of the 'family carers' <sup>a</sup> who look after terminally ill adults in home settings, and how can these needs be met by specialist palliative care teams and other generalist staff such as district nurses? A great deal of research has attempted to address these questions <sup>1-5</sup>, spurred on by the international policy shift towards facilitating home deaths over the last four decades <sup>4-8</sup>. The research effort on family caregiving has been motivated, in the main, by the imperative to train health and social care professionals to recognise and support the needs of caregivers in community settings, during both the dying and post-bereavement phases (whether patients have malignant or non-malignant conditions) <sup>1-5, 8-15</sup>.

Despite this research effort it is recognised that knowledge remains incomplete <sup>11, 3</sup>. When Harding *et al* <sup>11</sup> published the results of their systematic review of robust professional intervention studies designed to support caregivers' needs and preferences in community contexts they concluded that the range of models employed remained narrow and unsatisfactory. Such shortcomings were also highlighted in the authoritative ten-point 2014 European Declaration on Palliative Care <sup>16</sup>, with its 5<sup>th</sup> recommendation stating that policy and decision-makers at regional, national and international levels must:

(5) Promote a paradigm shift in health and social care towards basic palliative care skills for all health care professionals, to empower them to deliver patient-centred family-focused care for all people with a life-limiting illness, based on personalised or tailored care plans, with attention to all needs of the patient and his or her family. (p.5)

**Commented [CT1]:** Two new references have been added to this paragraph (Knighting et al, Harrop et al), As a consequence, all reference numbers have been changed throughout the paper.

This is where the UK study reported here can make an original contribution to knowledge about family carers' support needs<sup>17,18</sup>. Our aim in this paper is to explore findings that emerged through the narrative analysis of interview transcripts and drew attention to the existence of what we now conceptualise as 'relevant background worries' (RBW) in the minds of family carers. In retrospect, it is clear that such worries tend to be perceived within European and North American professional palliative care cultures as 'second-order' concerns, concerns that can legitimately be set-aside because time is limited and there are more pressing 'priority' needs. Indeed, there is a professional consensus that the 'priority' support needs of both patients and family carers are: keeping the dying person safe and secure; attending to patients' basic bodily functions; enabling carers to manage drug-regimes, health technologies, and complex symptoms; advising carers on how to deal with their own physical exhaustion and psychological distress<sup>1-3, 11-15, 19-21</sup>. However, our evidence suggests that the relegation of relevant worries to the background may understate their impact on family caregivers' ability to cope with caring for a dying patient and/or with the bereavement phase. Indeed, our findings suggest that the psychosocial wellbeing of family carers may be seriously affected by the presence of worries that caregivers keep out of immediate sight, and do not talk about unless asked. Our definition of this new concept is as follows:

**Relevant Background Worries (RBW):** second-order worries that occupy the minds of family carers and are of relevance to caring activities and emotions.

Two questions are immediately posed:

- Are family carers' relevant background worries (RBW) important enough to be identified and responded to as support needs?

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- If they do amount to support needs, how can these relevant background worries be identified and responded to? Meeting such support needs has time and skill implications for specialist palliative care teams and other generic staff such as community nurses.

First, we turn to our evidence for the presence of relevant background worries among family carers.

## 2. Design and Methods

The parent study that is drawn upon here was a qualitative cross-sectional observational investigation into the experiences of family carers who had recently looked after an older dying adult (aged 50 years or above). This study was conducted by a multi-disciplinary team in two sites in England, UK (2011-13): the North West (Lancashire and Cumbria) and South West (East Devon) <sup>17,18</sup>. These regions were selected because they both have high proportions of older residents but display contrasting socio-economic profiles (East Devon being the wealthier region). The research team was experienced in managing the sensitivities involved in palliative care research, and ongoing feedback from service users proved to be a crucial element of the project's success. [Ethical approval for the study was awarded by the National Research Ethics Service \(NRES\) Committee North West \(Ref: 11/NW/0203\), and governance approvals were sought and given from each participating NHS organisation. All study participants gave written informed consent to take part in the interviews.](#) Data were collected over 16 months in 2011-2012.

### Main sample construct

Study participants were bereaved family carers purposively recruited by staff in GP practices <sup>17,18</sup>.

*Inclusion criteria:*

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- Family carers of older deceased people (aged 50 years +) from any cause of anticipated death;
- Death occurring in the home of the patient or carer;
- Two weeks minimum period of family care prior to death;
- Any age of adult carer (excluding children);
- Participants recruited at least 6 months, but not more than 24 months, following the death.

*Exclusion criteria:*

- Sudden deaths e.g. stroke, myocardial infarction ;
- Death in hospital or other institution;
- Less than a two-week period of family care at home prior to death;
- Carers below age of 18;
- Participants in early bereavement (less than 6 months) or more than 24 months.

[INSERT Table 1 around here]

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Data collection

Data were collected through in-depth semi-structured interviews in participants' homes with an achieved sample of 59 bereaved carers (41 female; 18 male). An interview schedule was developed by the research team to elicit chronological experiential accounts by family carers. Interviews covered the dying phase, the death itself, and life post-bereavement. Two project researchers conducted the interviews, each around an hour in length (min. 15 minutes; max. 102 minutes, mean 47 minutes). Interviews were digitally recorded and then fully transcribed. Family carers were invited to talk about their experiences in a naturalistic story-telling fashion.

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### Sub-sample: Narrative analysis

The study employed two modes of qualitative data analysis, one of which is drawn upon in this paper (the other being the use of standard cross-sectional content analysis employing constant-comparative techniques – across the whole data-set). The data reported here involved the narrative analysis of a sub-set of 30 interview transcripts (15 from each region). This sub-set was purposively selected with reference to [the following factors \(see Table 1\): to focus more on carers who were either older or were daughters/sons; to achieve a regional balance; to ensure](#) a mix of respondents by family circumstances (i.e. relatively normative or complex). Although narrative analysis remains relatively new in specialist palliative care research <sup>21</sup> its utility as a sub-genre of qualitative research methodology is common in the social and health sciences, particularly in case-comparison studies of illness experiences in the UK and North America <sup>22-25</sup>.

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The approach to narrative analysis adopted here drew, in particular, upon the narrative research pedagogy of Mishler <sup>26,27</sup>, Reissman <sup>28</sup>, and Thomas <sup>29</sup>. The first stage involved developing and deploying a narrative analysis framework that enabled three analysts to identify the narrative threads or storylines<sup>26</sup> that ran longitudinally through each interview transcript, and to collectively explore the interrelationship between these threads. The lead author then undertook a second-stage narrative analysis in order to disentangle the main and background storylines. These analytical stages alerted us to i) how the bulk of family carers' experiential accounts focused on the health and comfort needs of patients, ii) that all narratives were interwoven with biographical storylines associated with individuals' life histories and identities <sup>22, 26-31</sup>, and iii) that relevant background worries (RBW) featured in the majority of sampled caregivers' narratives but varied in their nature, personal significance and [emotional](#) intensity. Relevant background worries associated with the dying episode itself, or with early bereavement, were storylines that surfaced periodically

and/or recurrently in individuals' accounts. Such worries were usually mentioned reluctantly and apologetically, and were articulated in interviews only when the family carer felt assured that it was legitimate to talk about their own concerns. These storylines sometimes began with statements such as: 'Should I have done that....?' or 'Would it have been better if we'd.....?'

### **3. Results: case-studies illustrating 'relevant background worries' (RBWs)**

We present four family carer case-studies: Ken (husband), Julie (daughter), Joyce (wife) and Gretta (wife) (all names are pseudonyms). These illustrate the difficulties and tensions that can arise in home death scenarios, and provide examples of different types of caregivers' relevant background worries. Before outlining each in turn, it is important to restate that all family carers in the sub-sample talked about meeting what were perceived to be the priority needs of the patients, that is: keeping the patient safe and attending to the persons' basic bodily functions; managing drug-regimes and health technologies; and dealing with the complexity of symptoms <sup>11</sup>.

**Case 1 (Ken, B14).** Ken was interviewed about the death of his wife, Marie, from cancer – a few months previously. The cancer diagnosis was recounted as a sudden shock to both of them, and death occurred several weeks afterward. They were a professional retired couple, without children. Much of the interview focussed on three themes: the complexity of the formal care input, on Marie's personal social care arrangements, and on Ken's responsibility for administering medication. The care package received was comprehensive, though perceived by Ken to be somewhat fragmented and uncoordinated in the early weeks. Ken reported that the *Hospice at Home* service introduced in Marie's final weeks had worked effectively for both Marie and himself.

A nuanced *relevant background worry* that recurred in the interview concerned *words not spoken* between Ken and Marie. From Ken's point of view, Marie decided to "turn to the wall" when she found out that she was terminally ill; she preferred to stay upstairs rather than sit downstairs or in the garden. Marie did not want to see her friends with the exception of one who was a retired nurse; this nurse became involved in the care arrangements.

Ken: it was almost as though she'd said, "That's it, it's over". That was a bit hard to take. ... Well that's how it started and that's how... I mean, I must say, once the diagnosis was made...

Later, he commented:

Ken: ... if I wasn't sort of preoccupied with the practical things, I could have given... been more emotionally involved.

Interviewer: Right.

Ken: Whether that would be good or bad I don't know. I suspect that she wouldn't have wanted that actually, that she really wanted... it was as though she'd opted out, "That's it... bye", kind of thing.

When it came to talking about the death itself, Ken outlined the events in much detail, but also returned to the story-line of his background worry and regret:

Ken: I didn't really take on board [being told that she could hear me] and so I didn't talk to her... How do we know they're at peace? She wasn't talking. I wasn't even talking to her,

for heaven's sake, which I should have done, and I regret that. I was just sitting there holding her hand and whether she was aware I was there or not I don't know. I mean there's this point where ... somebody's gone away from you. I suppose that had been happening for a week or two, you just don't know how far away they are ...

At the end of the interview, Ken once again expressed his puzzlement about Marie's unwillingness to talk about her situation. He noted that this had left him with unanswered questions about whether it was best that she had died at home rather than at the local inpatient hospice<sup>b</sup>. Overall, he acknowledged that such uncertainties might have led him to feel depressed – had he not managed to “retain full control of his life”.

**Case 2 (Julie, A11).** This case concerns the death of Frank from cancer, in the home of his daughter, Julie. Julie lived with her husband and was interviewed, after her father's death, about caring for Frank for 18 months. Much of the interview focused on Frank's steady physical decline and loss of independence, leading Julie to insist that he move into her home to be cared for. Julie described caring for him as exhausting and frustrating – because she found him to be “difficult”, “stubborn”, “obstinate” and an intensely “private” man. Frank had a long-standing hostility to hospitals and formal carers, and was “in denial” about dying until the final two weeks of life:

Julie: ... had I known quite how difficult it would be in the last few weeks, particularly the last week, I don't know if I would have gone down that route. And certainly had it gone on any longer I think I would have been saying “look dad, you've got to go to hospital” – because it was incredibly physically as well as mentally draining, and he was very awkward. He was never an easy person to be with or to live with, or to do anything with, and trying to

cope with it while he was ill and couldn't do anything himself ... was very difficult. So with hindsight I think ... I would have said "Oh dad, you know we can't cope, we'll either have to get carers in, or you'll have to go to hospital". But that would have been a very difficult decision to have made.

Despite these challenges, Julie made a point of saying that she loved her father. There is clearly evidence of a relevant worry about her father's character in the above, but this worry was linked to another *relevant background worry* and regret that crystallised as the interview proceeded. This underlying story-line was not about her father's death *per se*, but about the death of her mother some years previously:

Julie: [My mother] had to go into [hospital]... but she had gradually deteriorated, she wasn't being fed properly. Dad and I ... used to go in every single day. I used to go for mid-day meals, stay for hours, dad used to come to make sure she had [a meal]. But he wouldn't have her home again, and I had to fight to get her home because I knew she wouldn't live long. [I had to] fight dad and the hospital – because I wanted her to die at her home, not in hospital. I felt it was her right to die at home. But as soon as I got her home, two days later I became so ill myself that I spent six days in bed – I couldn't do anything about it. The first day after she was home I went, and dad said to me "I can't cope, I don't want carers in all the time, she'll have to go back, I'm going to put her in a home" – and mum heard, and I think she gave up. And I feel guilty because I couldn't go back [to see her]... It was only during the last three days that I saw her, and she had shrunk. She'd stopped eating, and I was trying to spoon food into her. Dad made her get up and hoisted her out of bed and put her in a chair, "she's got to sit at the table to eat, I'm not spoon feeding her in bed". And yet

I did all that for dad. I felt terrible [then], and I didn't want to feel terrible again [starts to cry].

This relevant background worry about the way her mother's life ended played a key role in Julie's determination to care for her father at home, and she now felt "relieved that I did the best thing that I could have done":

Julie: I have a very, very clear conscience now, and from my point of view that is so important because I had a bit of a guilty conscience about my mum.

Thus it was guilt and regret about her mother's death that had propelled Julie to take on the care of her father, and to embrace the associated emotional stress and physical exhaustion involved.

**Case 3 (Joyce, B13).** Joyce, aged 82, was interviewed about the death of her husband, Bill – eight months after his death at home. Bill had lived with Parkinson's disease for many years, and had developed dementia in the year before his marked physical decline and eventual death. Two adult daughters were present when he died at home, but did not reside near enough to provide regular care. In her interview, Joyce painted a picture of a long and very happy marriage. Repeated references to Bill being a "very good father" and a "loving husband" conveyed the story of a stable and joyful domestic life, leading Joyce to insist that she had wanted to care for him at home until his death. She had witnessed his distress during earlier hospital admissions, and "knew" that he wanted to be at home:

Joyce: I look back now, and I know I did the very best I could for him, and that's a comfort, because I wouldn't have had it any other way. He was a very good husband and, as I say, a very beloved father, and I owed it to him, you know... I owed it to him ... He was always very much a man for home and for his family.

Detailed care arrangements had been put in place by the GP once it was known that Joyce wanted end-of-life care to be home-based, and most of the interview explored the following: her experiences of coordinating with the formal carers; the challenges involved in managing her care duties; the equipment needed in the final weeks of life; and Joyce's exhaustion and worry. Joyce described how all went well with the practical care arrangements, after a room downstairs was re-organised and equipped to meet Bill's bed-bound care needs. Joyce slept in that room too, in order to attend to Bill's needs through the night. Nevertheless, a relevant background worry emerged as the interview progressed. This concerned Joyce's distress when Bill's dementia worsened and led him to mistake her for someone else; worse, he accused her of being a 'second wife' who was trying to poison him with the medication she was trying to administer:

Joyce: ... he thought I was trying to poison him!!... every time I gave him the pills I would stand over him and think he'd swallowed them [but] when I was making the bed more comfortable, I would find them under the mattress and... it was a real worry. And I said to the doctor, "Well what shall I do?"... because I thought he's going to die through lack of medication, and it's gonna be my fault. And [the GP] said, "Oh, at this stage don't worry about it. Just get them in if you can and if you can't, don't worry about it"....

... Actually, the psychological effects were the worst because we'd always been happy together; we'd never quarrelled... quarrelled maybe twice in our [marriage] ... and we were

married for 62 years. So when he turned against me I found that incredibly hard and... I could have done with some counselling then myself, I think, because, although you know basically it's not really them, it's the disease, it still hurts. ... I mean the physical things, they weren't pleasant but you can do it. I mean you do it for your children, so you can do it for your husband, can't you? ... It was the mental things that were the worst.

Interviewer: Because he didn't really know you, and he was...?

Joyce: He didn't (chuckles) – he had this complete fantasy: he thought that his first wife had left him – which was me – and that I was his second wife. And he was always telling me things that his first wife did for him that I wasn't doing (chuckling) you know. ...I didn't measure up to the first wife at all! When you get older, life is not as romantic as when you're young, is it? I think he looked at me and he saw this old person and he thought, "That's not my wife". That's the way I reasoned it out to myself. And that was pretty hard – because I was poisoning him, ... and I was having men in the house (chuckling) when I was 82 !! ... and I'd never had a man in the house in that sense... in all my life. Nor ever would have. And that was... it was incredible... I can laugh about it now, and yet at the time it hurt... I found it very difficult.

Bill's confusion and mistrust had clearly been a source of considerable distress to Joyce. Her relevant background worry revolved around the loss of Bill's personhood, and the loss of their mutual capacity to celebrate their long and happy marriage. Although she could laugh a little about it during the interview, the hurt and sadness obviously lingered.

**Case 4 (Gretta, B17).** There are some similarities between the above case and the life circumstances of Gretta and Max. Both were in their 80s, and Max was able to die at home with

Gretta's unwavering support, despite her own long-standing health problems. Gretta talked about her deep love for Max, and their long family-centred marriage. Their two adult daughters, now in their late 50s, lived close by and were able to provide some assistance with the care work. Like Joyce, Gretta had chosen to sleep in a temporary bed in the dining room once Max was located there, in a loaned 'hospital bed' so that she could attend to his needs during the night. Gretta provided a detailed account of Max's painful terminal illness and death from a heart condition and septicaemia, noting that she had found "some comfort in being there".

The interview with Gretta was lengthy, and covered childhood experiences in war-time Germany as well as Max's long illness, care needs, and days of dying. End-of- life care arrangements had involved two GPs, district nurses, and a hospice out-reach team. Gretta was appreciative of what she perceived to be very good formal care services, making only one mild criticism centred on the change in nursing staff as death approached; that is, moving from district nurses to an unknown team of palliative care nurses:

Gretta: When [the district nurses] came, they said, "Go on, Gretta, sit in a chair." They'd make me a cup of tea and I'd relax, you see... ... it had taken me a long time but I learned to relax, and I just sat there. I made my brain absolutely blank, because the rest of the time you have to think... [The district nurses] were lovely. [So] I didn't feel I could bring another whole crowd in.

However, the relevant background worry we wish to feature here became evident in the final stages of the interview, and concerned Gretta's life after her husband's death. This was her surprise at the way some former friends had responded to her new situation:

Gretta: But what disappointed me most was... one couple we were always very friendly with ... After Max had died, well, she couldn't cope with illness so she never phoned or never asked how I was. [Her husband] came to start off with, and visited Max, but once he died both of them dropped me like a hot brick...

[Later] I had to get in touch with them and I was told, erm... "widows are pushy". And I said, 'What do you mean, widows are pushy?' And they couldn't really give me the right explanation... I said, "I haven't pushed myself onto you". I said, "You have never phoned me and asked me how I was, and I never pushed myself onto you, so whatever do you mean?" And I was very cross with him, and very hurt... ... I've never seen them again, and that's a couple we were friendly with...

And it is completely... as if you are a leper to some. I really felt that. I don't count nowadays... But other [widows I've spoken to] said they have felt the same, that you just get somehow 'dropped'.

Gretta went on to explain that her age meant that many friends and family members had died, or become ill, including a close female friend who had developed dementia:

Gretta: ...one who was my colleague [when I worked], she has got dementia... she was my real good friend. She's still alive but, of course, it's not that I can ... she doesn't... she just sort of... yes, occasionally I show her photos of the times we had. But, erm... but I don't have the old friends left here.

Thus, Gretta's social network was much reduced, with some former friends being lost for reasons that she found difficult to comprehend and accept. This relevant background worry about others' responses to her widowhood draws attention to some of the social-relational difficulties faced by family carers in the post-bereavement phase.

## **5. Discussion**

### *Results of the study*

In our view, the relevant background worries that Ken, Julie, Joyce and Gretta spoke about in interviews constitute psycho-social factors that impacted on their actions and emotional wellbeing, either during the dying period itself and/or in the post-bereavement phase. Taking each case in turn, it is helpful to speculate on the health benefits that could have been delivered by specialist palliative care teams and generic staff if the relevant background worries had been identified as support needs, and responded to appropriately. Ken (case 1), for example, had not understood that his dying wife was probably able to hear his voice when he sat with her at the end of her life. This suggests that he, and his wife, might have benefitted from clearer information from palliative care professionals about a dying person's capacity to hear and comprehend. Moreover, Ken's bereavement may have been eased if he could have subsequently discussed his uncertainties and regrets about not communicating with Marie with a trusted bereavement counsellor or volunteer. Julie (case 2) had continued to struggle to care for her dying father, despite his challenging personality and stubborn resistance to care services, because she had felt guilty about not "being there" for her dying mother in previous years. If a professional had detected what underlay these father/daughter tensions at an early stage, Julie might have received the service assistance that she needed when her father was dying. Indeed, Julie could have discussed whether she had the right to involve formal care services despite her father's resistance. Joyce (case 3) had experienced

considerable distress and sadness because her husband's dementia-related behaviour had caused him to accuse her of gross deceit, something that she was reluctant to talk about. Joyce's effort to care for Bill may have been made more bearable if professionals had detected and talked through these inter-spousal difficulties. Joyce may also have benefitted from counselling about her distress at the post-bereavement stage. Gretta (case 4) had been shocked and upset by the chilling reaction of former friends to her widowed status. She might have benefited from talking through some of these hurtful background experiences in post-bereavement counselling. Indeed, it may have been appropriate for Gretta to be warned by professionals, in advance, about the potential disruption to friendship networks caused by deaths.

These speculations mean that, for these particular cases, our answer to the first question posed earlier is 'yes'. That is, these family carers' relevant background worries (RBW) were important enough to be identified and responded to as support needs. However, such views are contentious and others may disagree and/or may respond that resource constraints would not allow such support needs to be uncovered and/or addressed in reality. That is, it may be argued that, in practice, decision-making on what constitutes a carer's support need will depend on many circumstantial factors.

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#### What this study adds

If palliative care teams thought that some of the carers' relevant background worries were important enough to constitute support needs, then, in our view, the 5<sup>th</sup> recommendation in the 2014 *European Declaration on Palliative Care* <sup>14</sup> (cited above) would have moved closer to becoming a reality. That is, personalised and tailored care plans would be facilitated, improving the

quality of care in community settings. But how could this be achieved for family carers collectively given the resource pressures involved in meeting a wider set of support needs? A host of follow-on questions are raised, for example: do specialist professionals and generic staff/workers have the time to listen carefully to family carers' relevant background worries? Do professional teams have the skills to 'listen-out for' or 'pick-up on' caregivers' personalised worries, and do they have the skills to decide which RBW is important enough to designate 'a support need' worthy of intervention? Does uncovering the presence of relevant background worries require a special type of trained sensitivity?

These challenging questions will, hopefully, stimulate professional debate. Such debate **should** interconnect, **in appropriate ways**, with palliative care cultures that operate in diverse global regions <sup>31</sup>. In our view, on-going debate on such matters is **to be welcomed** in order to enrich formal care packages, and to promote the called-for paradigm shift in palliative care in Europe <sup>16</sup>. One suggestion for action is that commonly used clinical tools, such as the Carer Support Needs Assessment Tool (CSNAT) <sup>32,33</sup> or the self-completion Caregiver's Burden Scale in End of Life Care (CBS-EOLC)<sup>34</sup>, are used to draw-out and understand the significance of relevant background worries **(for other resources, see also Knighting et. al. <sup>4</sup>, and Harrop et. al. <sup>5</sup>)**. For example, the 16-item CBS-EOLC scale <sup>34</sup> contains questions that could serve as trigger conversation topics to be returned to and focused upon at a later date, such as the question: "Do you ever feel afraid that you won't be able to hold out much longer?". Of course, the selection of the person(s) in the professional team who has responsibility for this follow-up discussion with caregivers is a matter for discussion within the **team**.

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**Commented [CT9]:** An indication of other resources is added here.

**Commented [CT10]:** Wording is altered in this paragraph to include references to other tools and to improve clarity of meaning.

Another suggestion is that a member of the team is trained in narrative medicine or narrative therapeutics so that they become skilled in identifying the nature and significance of family carers' relevant background worries in end-of-life scenarios <sup>35-38</sup>. A third suggestion is that hospice volunteer workers who work in community contexts could assist with identifying and responding to family carers' relevant background worries because they are well-placed to form trusting friendships with caregivers <sup>3,39,40</sup>. With appropriate ethical consent, volunteers could inform their professional palliative care teams about the relevant background worries that family caregivers are harbouring – especially those which appear to be impacting forcibly on caregivers' actions and well-being. However, if the relevant background worries of family carers are thought to be too resource-hungry to respond to as support needs then, at least, knowledge about the presence of such worries may benefit caregivers in indirect ways.

Limitations:

A limitation of this paper is that the results section presents only four case-studies. However, it is in the nature of narrative analysis that individual cases are explored in detail, and we therefore concentrate on data-depth rather than data-breadth <sup>24-27</sup>. Far more space would be required to present more cases. [in our view](#), the relevant background worries featured in the four case-studies are [strongly indicative of the presence of support needs](#), but RBW of different types and [emotional intensity](#) were present in the majority of interview transcripts. [Whether the latter amount to support needs is a matter for debate – but their acknowledgement is a necessary precondition for such debate](#). The other limitations of the project are reviewed elsewhere <sup>17,18</sup> but include: the difficulties involved in recruiting bereaved people into the research study; heavy reliance on the recollections and accounts of bereaved family carers.

**Commented [CT11]:** Wording is added and changed in this paragraph to achieve greater clarity and precision.

## 6. Conclusion

This paper has reported on a study that used narrative analysis methods to explore the storylines present in 30 semi-structured interviews with family carers who had supported terminally ill adults who died in home settings. This analysis led to the conceptualisation of what are named ‘relevant background worries’ (RBW), a new concept that may also be useful in other clinical contexts. We define RBW as follows: second-order worries that occupy the minds of family carers and are of relevance to caring activities and emotions. These worries vary in their nature, significance and impact – and will certainly carry different meanings in diverse cultural contexts. Significant RBW were illustrated through the presentation of four case-studies, followed by a discussion about how these individuals’ worries could have been responded to if they had been identified as support needs. This led into a discussion about how RBW might be picked-up and addressed by professional palliative care teams and generic professionals/workers in service contexts.

Whilst the *priority* needs of patients and family carers must of course take precedence, it is our view that the quality of clinical practice could be improved if specialist palliative care teams in community contexts did extend their interest to family carers’ relevant background worries (RBW). However, this is controversial because resources are always finite<sup>42</sup>, and decision-making is required about which worries amount to support needs of significance and manageability. We suggest that the RBW that require attention are those that have significant psycho-social impacts on family carers’ actions and emotional wellbeing. This suggestion poses challenges, and links with other challenging initiatives such as the Scottish Chief Medical Officer’s call for ‘values based’ Realistic Medicine<sup>41</sup>. Our suggestion is given added relevance by the international policy shifts underway in resource-rich nations, such that deaths in home settings for terminally ill patients are both encouraged and achieved<sup>42-45</sup>. This means that family carers will be increasingly relied upon to

**Commented [CT12]:** New wording is used in this paragraph in an attempt to clarify meaning – especially how our new concept ‘relevant background worries’ emerged through the narrative analysis of interview transcripts..

deliver care to dying people, a trend that underlines the importance of providing support of the highest quality to family caregivers.

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## NOTES

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<sup>a</sup> In line with research in the palliative care field, this project used the UK's National Institute for Clinical Excellence's (2004) broad definition of *family carers* as people with a close social and emotional bond to the patient. Such carers are not just those related by kinship or heterosexual marriage. Thus the standard sociological term 'informal carer' has been replaced with 'family carer' or, sometimes, the North American term 'caregiver'.

<sup>b</sup> In the UK a hospice is a local institution with inpatient beds, usually funded by voluntary means. 'Hospice care' may carry other meanings in other countries.

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