"You only have one chance to get it right": **a qualitative study of relatives' experiences of caring at home for a family member with terminal cancer**

Jonathan Totman[1]; Nancy Pistrang[1]; Susan Smith[2]; Susan Hennessey[3]; Jonathan Martin[4,5]

[1] Department of Clinical, Educational and Health Psychology, University College London

[2] Dimbleby Cancer Care, Guy's and St Thomas' NHS Foundation Trust

[3] Barts Health NHS Trust

[4] St Joseph's Hospice Hackney, London

[5] Harris Manchester College, University of Oxford

CORRESPONDENCE ADDRESS

Research Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London WC1E 6BT, j.totman@alumni.ucl.ac.uk

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ABSTRACT

Background: Relatives looking after a terminally ill family member at home face numerous challenges. Studies into relatives' experiences of home caregiving have been criticised for their descriptive nature and lack of theoretical underpinnings.

Aim: To explore the emotional challenges faced by home caregivers, and their experiences of healthcare professionals, from the perspective of existential psychology.

Design: A qualitative study using semi-structured interviews. Transcripts were analysed thematically using the Framework approach.

Setting/Participants: The study took place within an inner-city London hospice. Participants (n=15) were recently bereaved adult relatives of cancer patients who cared for their family member at home.

Results: Participants' experiences of being a caregiver and of professional support were highly varied. The analysis generated 15 themes which were organised into a framework based on Yalom's 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. "giving something back", "acceptance and gratitude"). Healthcare professionals were perceived as influential in both helping and hindering relatives in meeting the challenges they faced.

Conclusions: Existential psychology provides a theoretical perspective from which to understand the psychological complexity of the emotional challenges home caregivers face and a framework which may usefully inform research and clinical practice. Professionals' attentiveness to caregivers' needs can have powerful effects in assuaging anxiety, reducing isolation, and enabling relatives to connect with the meaningfulness of caregiving.

KEY STATEMENTS

What is already known about the topic?

- Relatives looking after a family member with terminal cancer at home often face numerous challenges and are at increased risk of poor physical and mental health.

- Our current understanding of caregivers' experiences and needs during end-of-life care is limited by a relative neglect within the literature of established theory.

What this paper adds?

- Using the theoretical framework of existential psychology, the study adds clarity to our understanding of the emotional challenges faced by home caregivers, and how healthcare professionals' actions and inactions may impact on their coping.

- The findings point to the psychological complexity of the challenges associated with home caregiving, including: exceptionally high levels of responsibility; a sense of profound isolation; and anxiety elicited by confrontations with death and dying. At the same time, caregiving can be experienced as a deeply meaningful endeavour, particularly for those who are well supported.

- The study also indicates the variability of caregivers' experiences and current shortfalls in service provision.

Implications for practice, theory or policy?

- The study highlights the crucial importance of reliable, proactive and well-coordinated professional support for caregivers and the damaging consequences where this is perceived to be lacking.

- Interventions for informal carers in palliative care might usefully address existential concerns, and healthcare professionals should be mindful of these issues in their interactions with patients and families.

- The findings also speak to the power of practical support and ostensibly simple gestures beyond their immediate, tangible effects – being willing to listen, providing reassurance, and holding relatives in mind may be profoundly important at this time.

INTRODUCTION

As the population ages, and more people are being cared for in the community, relatives and informal caregivers are playing an increasingly important role in looking after those with a terminal illness.[1,2] Provision of support for carers has been identified as an under-acknowledged priority,[3] with a recent UK government survey suggesting that only 50% of family carers get as much support as they want during the last three months of their loved one's life.[4]

It has been argued that the idealisation of home-based care downplays the complex challenges caregivers face.[2] Often, relatives take on high levels of responsibility, and studies indicate they are at increased risk of poor physical and mental health.[5–7] Feelings of inadequacy,[8] helplessness,[5,9] confusion,[10] and fear[11] are common.

Research has gone some way towards helping us understand carers' needs.[12,13] Studies have described the importance of reliable practical, informational and emotional support[7,9,14,15] and the sense of security a responsive team can foster.[16,17] In contrast, inadequate or conflicting information, unresponsive or impersonal care, and discrepancies between decisions and interventions, can have profoundly deleterious effects.[17,18]

As well as facing the loss of a loved one, family caregivers may be threatened with the loss of important goals, values, roles and beliefs.[19] Yalom argues that a confrontation with death can be an "awakening experience", a time of existential suffering, in which the transience of life is brought forcefully into awareness.[20] Despite its relevance to palliative care, existentialism as a theoretical perspective has been relatively absent within the literature.[21,22] Studies of carers' needs have been criticised more generally for their neglect of theory,[13,21] contributing to a degree of fragmentation within the literature.[23] Within psychology and psychotherapy, existentialism is concerned with the experiential conditions of human existence. Synthesising

the work of a host of existential writers, Yalom[20] outlines four "existential conditions": freedom (and its corollary, responsibility); isolation; meaninglessness (and the need to find meaning in life); and death. According to Yalom, these are fundamental anxieties which both haunt and propel us in our life endeavours; often kept out of awareness in day-to-day life, they confront us in particular at times of crisis.

A recent review examined the literature on existential concerns for relatives of patients receiving palliative care.[22] Seventeen studies - with a range of foci, participants and settings - were included. Of these, most did not focus specifically on existential issues but looked more broadly at relatives' needs. In one exception, Albinsson and Strang[24] used Yalom's framework in a qualitative analysis of existential concerns among relatives of dementia patients living in nursing homes. The authors found that Yalom's four conditions readily captured themes in participants' experiences (e.g. *Obligation-guilt*, *Being the only relative*), and argued for the need for greater appreciation of existential issues in clinical practice and research. Another study with home caregivers focused specifically on the construct of meaningfulness, [25] highlighting positive dimensions to caregiving – something often overlooked in the literature. [14,26] The authors of the review conclude that further research is needed to better understand the existential challenges faced by relatives in palliative care and how professionals can support them.

The present qualitative study addressed the following questions, approached from the perspective of existential psychology: 1) What are the emotional challenges experienced by relatives caring at home for a family member with a terminal illness? 2) How do relatives perceive healthcare professionals as helping or hindering them in dealing with these challenges?

METHODS

Setting and Recruitment

The study was carried out within the community palliative care service of an inner-city London hospice. Ethical approval was obtained from the University College London Research Ethics Committee and locally from the Hospice Research Governance Committee. 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.

2. The patient's death occurred approximately three months previously. This time-duration, for which there is precedence in the literature,[9] 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.

3. Minimum age of 21.

4. Fluency in English.

Consecutive patient series sampling was used, whereby all participants meeting inclusion criteria during the study period were invited to participate. Participants gave written consent prior to the interview. Interviews lasted approximately one hour and took place either at the hospice or participants' homes. Recruitment ceased when a rich data-set had been obtained, capturing both common themes and variability in relatives' experiences.

Interviews and Analysis

Interviews followed a semi-structured format. An interview schedule was developed based on the research questions and guidelines on qualitative methodology.[27] Interviews explored the whole caregiving trajectory, including participants' experiences of professional support (both

from the hospice and elsewhere). They were designed to be minimally directive, enabling participants to describe what was important to them.

Interviews were audio-recorded and transcribed verbatim. The data were analysed with the aid of NVivo software (QSR International) using the Framework approach,[28] a form of thematic analysis.[29] The research questions guided the analysis, i.e. specific aspects of the data, relevant to the research questions, were analysed in detail. The first step was to generate tentative themes representing the meanings expressed in each transcript. Subsequent cross-case analysis involved identifying patterns across the data set, refining and synthesising themes by scrutinising them for coherence and distinctness; this was an iterative process whereby themes were refined with repeated checking of the raw data. A series of (electronic) charts was then produced to record the data indexed under each theme for each participant. This provided a further checking process as gaps in the charts were identified, and facilitated comparison across individuals and themes. In determining themes, attention was paid to the frequency of relevant material both across the data set and within individual transcripts.

The incorporation of the theoretical perspective of existentialism provided both a framework for the analysis and a further source of insight into the data, helping to enrich and develop the emerging themes. [30,31] Braun and Clarke describe this as "theoretical thematic analysis" – an approach in which aspects of the data are foregrounded in line with a pre-existing theoretical model. [32] We did not wed ourselves to Yalom's model from the outset; rather, this was incorporated only after the initial stages of analysis, when thematic resonances emerged. In adopting this approach, it was important to avoid shoehorning the data *into* the theory. Through a collaborative process of analysis, it was decided that Yalom's "existential conditions" provided a useful organising framework for the material, and a potentially illuminating lens on participants' accounts.

Steps were taken to ensure the credibility of the analysis in accordance with published guidelines.[33–35] First, a team-based approach was used to share ideas and guard against bias. Prior to the analysis, the research team independently read a selection of transcripts and generated ideas on themes which guided the initial coding. Periodic meetings were scheduled throughout the analysis in which the coherence of themes was discussed and the final framework agreed upon. Second, testimonial validity checks[33] were used, whereby participants were sent summaries of the themes in their interview and invited to provide feedback. Summaries were sent to all but one participant (whom we were unable to contact) and seven replied. Of these, six said they were happy with the summary, one suggested minor amendments in emphasis. Third, steps were taken to "bracket" our assumptions and guard against the unwarranted imposition of theory onto the data.[36] Through frequent group discussions, we endeavoured to reflect on and make explicit our preconceptions, "shelving" our own ideas where necessary to make room for alternatives. [37,38] For example, given that most of the researchers were practicing healthcare professionals, it was important to reflect on the potential influence of our professional experiences on the analysis. Our intention was not to discount our own thoughts, but to ensure the analysis was not driven by idiosyncratic ideas at the expense of the data.

RESULTS

Characteristics of participants

Of 25 eligible participants, 15 consented to take part and 10 declined. The main reasons for declining were not feeling emotionally ready and not having time to attend an interview. Table 1 shows participants' demographic characteristics. Ten participants were working at the time of the study and five were either retired or unemployed. Six 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.

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 the patients were cared for and eventually died at home but almost all also had periods of time as an inpatient either in a hospital or hospice. All received medical and social care from multiple services. The duration of patients' illnesses from diagnosis to death ranged from several months to five years.

Table 1

Overview

The analysis generated 15 themes (Table 2), organised into a framework based on Yalom's four "existential conditions": responsibility, isolation, death and meaningfulness (the reverse pole of Yalom's category "meaninglessness" was used as this better fit with participants' experiences). The themes are described below along with illustrative quotations. Across the sample, experiences of being a caregiver and of professional support were varied. Six participants had, on the whole, positive experiences of services, five had particularly negative experiences, and four were more mixed.

Table 2

1. Responsibility

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

A central theme concerned the exceptionally high levels of responsibility participants experienced. Relatives were repeatedly faced with decisions about their family member's care, the weight of which were heightened by the thought that the patient's wellbeing, and even their life, 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)

Professionals could make a big difference in easing or exacerbating the burden of responsibility.

> *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 some participants, the support network provided a sense of security and shared responsibility, underpinned by a reliable care package. Particularly important for relatives was reassurance that they were doing all that they could. Others, however, felt alone with their responsibilities and let down by services - including GP surgeries, hospitals, district nursing and, sometimes, hospice care. The five who had more negative experiences overall described prolonged excessive levels of responsibility. They found themselves in the position of coordinating the patient's care, constantly having to *"fill the gaps"* (P14) where communication between professionals failed.

> *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 [uncle]. Always, always on the phone.* (P2)

1.2. Constantly on the alert

The extent to which this responsibility permeated participants' lives was striking. Relatives described living 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)

Particularly for those who lived with their family member, caring became an all-consuming job, occupying them *"every waking moment"* (P1). Many described a constant *"dread"* (P1,6) of something happening to the patient in their absence, and participants often put their family member's needs above their own.

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

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

Participants also felt responsible for ensuring their family member's death happened in the right way. This meant, for example, enabling their wish to die at home, respecting their religious beliefs, advocating for their needs, or ensuring they were not left alone.

> *You only have one chance to get it right. So you do put absolutely everything into it. When we were looking after her...there was never a moment when she was alone.* (P12)
> *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)

"Getting it right" (P12) could be a nebulous responsibility and a source of anxiety, particularly when participants had to *"juggle"* (P7) competing views (e.g. religious beliefs vs. medical information) and commitments (e.g. work and childcare), and when their ability

to care was compromised by factors beyond their control such as financial restrictions or lack of support.

1.4. "Am I doing enough?"

Relatives also became very conscious of themselves as decision-makers. This was new and unprecedented territory for most, and often elicited anxieties about what one "ought" to be thinking, feeling and doing.

> *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?" (P7)*

Two participants in particular described repeatedly questioning whether they were doing enough, afraid of missing something important. Several others criticised themselves for finding things hard or taking time off.

> *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)*

Similarly, several participants spoke about navigating the agonising decision of when to ask for more help when so much was at stake.

2. Isolation

This category concerns participants' experiences of relationships with the patient, friends and family members, and healthcare professionals. The themes illustrate the profound sense of isolation caregivers often experienced and the role of supportive others in mitigating this.

2.1. Being on my own

Feeling unsupported gave rise to feelings of isolation. Most participants mentioned at least one occasion when they felt let down by professionals, and several described the desperation they felt when 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)

The period following a patient's discharge from hospital could be particularly challenging, as 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)

Participant 15 described the isolation she experienced after moving to live with her mother, linking this with having to readjust her expectations of professional services:

> *So I was there and felt…felt…it was okay at the beginning, but as she got worse, I found it really difficult actually. And felt really isolated. I mean it was only her [mother's] friends and the neighbours actually, and my husband, who would come round, and the boys, that kept me going really. Certainly not [healthcare provider]… I expected so much, you know, but maybe too much, in my head, I suppose.* (P15)

For the five participants who had particularly difficult experiences, there was a sense of embattlement; of having to fight for their family member's 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. Such experiences left participants with a sense of

the momentousness of their situations going unacknowledged or thoughtlessly dismissed. One participant voiced the emotional impact of finding herself unable to get hold of medical equipment for her mother:

> *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)*

Being unable to access help also evoked frustration and anger.

> *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)

2.2. Losing a relationship

Added to this were the challenges of adjusting to a changed relationship with the patient. Participants described the pain of witnessing the physical and mental suffering of their family member and the shock of realising *"that's not (him/her)"* (P3,5).

> *His whole personality changed, he [partner] 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. Becoming a carer meant navigating new boundaries in the relationship and relatives sometimes struggled with intimate aspects of care such as washing their family member. Similarly challenging were times when patients were reluctant to accept help and when relatives were on the receiving end of frustration or anger. One participant 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)

2.3 Being held in mind

Supportive others could impart a valuable sense of being held in mind, which mitigated feelings of isolation. Often there was one person or service that relatives 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, and ostensibly little things could make all the difference. One participant described how much it meant to her to receive a letter from a voluntary-sector organisation which focused solely on her needs as a carer. Participants often described wanting someone simply 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)

Similarly, relatives appreciated professionals' taking the time to explain things, showing sensitivity to their needs as well as the patient's. Several mentioned hospice staff specifically:

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 everyone mentioned friends or family as a source of mutual support - those who had more positive experiences made more references to their support networks. Being able to

share decisions with trusted others helped to reduce isolation and ease the burden of responsibility.

> *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)

3. Death

This category concerns participants' thoughts about the approaching death of their family member and death/dying more generally. The themes illustrate the anxiety such thoughts could elicit and the ways in which this was managed during caregiving.

3.1. Knowing but not knowing

Prominent in participants' narratives was a sense of the incomprehensibility of death. Some described a gap between knowing *"academically"* (P12) or from *"a professional point of view"* (P13) that their family member was dying, versus knowing *"emotionally"*.

> *Even though we were there and we knew she [mother] 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)

This was alluded to 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 also said that despite knowing what was going to happen, they still clung to *"that slight bit of hope"* (P7) and almost invariably the death itself came as a shock. Three participants said they blocked out difficult feelings in order to cope.

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3.2 Repeated confrontations with mortality

This dissonance was mirrored in fluctuations in understanding and readiness over time. Many participants referred to moments when they were jolted into awareness of their family member's impending death.

> *On the Sunday when I went to see him [brother] 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, he's dying", I could see he was dying.* (P6)

Some described their shock at the rapidity of their family member's deterioration; eight described the turmoil of repeatedly *"bracing"* themselves for the death and then *"deflating"* (P12) when it did not happen.

> *Because he [nurse] said 28-48 hours, so 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.* (P8)

Participants wanted professionals to speak openly to them about their family member's prognosis. In contrast, oblique communication led to confusion and a sense that things were being withheld.

> *And basically saying it how it is, there's no need to... 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 reliable; one participant emphasised the need for professionals to qualify uncertain statements which could otherwise provoke unnecessary panic.

3.3. Thinking about mortality

Seven participants referred at least once to 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

Three spoke more extensively about the significance of death within their worldviews, and how their beliefs and values helped them cope.

> *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)

3.4. Protecting family members from existential suffering

Relatives often strove to protect their family member from thoughts about death, disguising the prognosis and providing comfort through distraction. Two participants acted as translators at appointments and both described *"tempering the bad news"* (P12). On the other hand, one participant (P13) emphasised that for him and his mother, it was important within their religious values to openly acknowledge that this was the end of her life and to talk about it as a family. Many participants were afraid of their family member dying alone and some went to great lengths to prevent this.

> *...when I got back he [husband] 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 themselves were present at the end, either at the time of death or through their presence leading up to it, was a source of comfort.

4. Meaningfulness

This category illustrates how caregiving was often experienced as a deeply meaningful endeavour which, despite its challenges, also had positive dimensions.

4.1. Giving something back

Participants often spoke about wanting to give something back to their family member and being able to do so was a source of comfort.

> *I thought to myself yeah, you've [wife] 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)

For five participants in particular, there was a sense that they felt confident and supported in their roles, and had the mental space to reflect on the value of what they were doing and enjoy the time spent with their family member.

> *if there was a problem I'd get a call straight away and I could sort it or deal with it. So it was very reassuring from that point of view, very comforting. And also it meant – they (carers) used to do some cleaning, tidying, washing up, that kind of thing – so it was nice, it meant that when we were up there, we could actually spend more time talking to [Aunt].* (P4)

> *But really and truly all I did when I went over there was have quality time with him.* (P6)

4.2. Religion

Of the five participants mentioned above, four spoke about their religion, connecting caring with the values enshrined in their faith or finding strength and solace in their religious beliefs.

> *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 time before their family member's death; signs to them, for example, that deceased relatives had come for them.

4.3. Intimacy

Contrasting with and alongside experiences of isolation, participants also described ways in which they continued to enjoy their relationships. For some, the awareness of their family

member's approaching death spurred a resolve to make the most of the time they had together. Several participants mentioned rituals which meant a great deal to them at this time.

> *(I'd) 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"…And just really having total quality time.* (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 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)

4.4. Acceptance and gratitude

Participants often reflected on things they were grateful for. Many 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. Gratitude could also emerge when reflecting on and reappraising potentially distressing situations, as in this example given by Participant 6, whose brother's medication did not arrive as expected.

> *And, quite rightly, after speaking to my younger brother, he said well…they could have administered that drug at 2 o'clock, he [brother] 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.* (P6)

Three spoke more extensively about finding a level of "acceptance" that brought with it feelings of gratitude for their family member's life and for life itself.

> *At that time it was very difficult, you know, we're still recovering. But you have to accept it. Life is not always the way you expect it. Change will definitely come, whether it's come from God or Allah, or whether it's come from you, or whether it's come from the environment.* (P13)

One participant described how her encounters with death motivated her to *"live for today"* (P6).

DISCUSSION

The findings of this study are consistent with and extend those of previous research in highlighting the numerous challenges home caregivers face.[12] The theoretical lens used here provides insight into the psychological complexity of these challenges, and a framework for understanding them in terms of four key existential anxieties: responsibility, isolation, death, and meaningfulness. The findings also point to the importance of healthcare professionals in helping relatives to manage these challenges.

The themes within the category *Responsibility* were particularly striking in our data, and speak in particular to the home context. Consistent with previous studies, relatives frequently took on high levels of responsibility.[5,6,8] This study adds an understanding of how this responsibility was experienced as one of unique intensity, constantly challenging carers to step out of familiar roles and rise to the situation before them. As well as practical responsibilities, caregiving raised questions for relatives about their values and commitments and elicited a sense of responsibility to meet these at any cost. From an existentialist perspective, the urgency attached to "getting it right" can be understood as fuelled in part by relatives' awareness of the approaching death. Participants described the sense of immediacy and momentousness that pervaded this time, such that everyday concerns paled into

insignificance and caring became the ultimate priority. According to Yalom, the anxiety of responsibility is related to the dizzying freedom to choose, and the sometimes crippling knowledge that "alternatives exclude". In this study, relatives often felt thrust into their caring role by necessity and/or embraced it as a duty they expected of themselves. At the same time, they were often faced with agonising decisions, and the themes *Getting it right* and *Am I doing enough?* capture the conflict and self-doubt this could generate. Responsibility thus extended even to internal states as participants sought to master and not be paralysed by feelings and inhibitions.

The weight of decisions was heightened for those who felt alone with their responsibilities. For some, caring gave rise to feelings of isolation, exacerbated by difficulties communicating with family members and, sometimes, professionals. Relatives often felt a sense of loss on account of their family member's deterioration and their changed relationship with them. Carlander et al. suggest that caregivers face challenges to their self-image as they adjust to new roles and relationship dynamics. [39] 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 needs. This could give rise to a sense of being distanced from the patient, disconnected from familiar routines and, in some cases, profoundly alone.

A previous study found that the nearness of death often made it difficult for dying patients and their next of kin to talk openly with one another.[40] The current study further illustrates the complex and non-transparent ways in which thoughts and feelings about death are experienced at this time. Some relatives could not let themselves enter fully into the reality of what death meant, else they might, as one participant put it, *"crumble"* (P2). On the other hand, for some - particularly those with a strong religious faith - thinking about death and what it meant was described as an important part of preparing and grieving.

Yalom[20] contends that a confrontation with death can prompt a deeper appreciation of values and relationships, imbuing life with unprecedented meaningfulness. This was evidenced in the current study by the intimate moments participants enjoyed with their family member, and the sense of connection they shared with supportive others. Some participants also found strength and solace in religion, both through the belief in an afterlife and the meaningfulness of caregiving within their faith.

Frankl (1946) writes about the importance of a sense of meaning in enabling us to endure suffering, and our capacity to find meaning even in and through suffering. This was borne out in the current study by relatives' commitment to caregiving and the sense of comfort that came with knowing they did all they could. A small number of studies have also highlighted positive dimensions to caregiving, [25,41] and the role of meaning-making in adjustment following bereavement. [26,42] It was notable here that participants who spoke more about the meaningfulness of caregiving tended to have more positive experiences overall. Furthermore, it seemed that feeling well supported contributed to relatives' freedom to connect with the positive, meaningful aspects of caregiving.

The findings highlight the crucial importance for relatives of reliable and proactive professional support. With increasing value being placed on home-based care in local and national policy, it is vital for services to be attuned to the implications for relatives, and to ensure that rhetoric does not obscure or add to the pressures they face. Our findings suggest that being in receipt of specialist community palliative care does not guarantee that caregivers feel adequately supported, and services need to be vigilant in addressing the needs of those who become isolated and overburdened.

In the uncertain context of end-of-life care, professionals' words and actions carried great weight for relatives, and ostensibly little gestures often carried great meaning. Particularly

valuable were interactions in which professionals showed an interest in relatives' experiences and a willingness to listen. In contrast, dismissive or impersonal communication had a starkly isolating effect. The importance of empathic communication in this context is neither new nor ground-breaking; [43,44] however, this study highlights its power in mitigating isolation, assuaging anxiety, and maintaining caregiver-professional relationships. The heightened significance of professionals' actions at this time, and the importance of interpersonal connectedness, can perhaps be understood by appreciating the existential anxieties relatives may be grappling with; according to Yalom, it is through relationships that these anxieties are endured. Importantly, just as individuals could be perceived as insensitive, so too healthcare services could be perceived as preoccupied or neglectful. Particularly detrimental were perceived failures in the coordination of care. A previous study identified "easing the burden of advocating for the patient" as a key aspect of support for carers.[45] The present study reveals the risk to relatives when this burden is shouldered alone for too long, and hence the importance of effective multi-agency working.

This study has several limitations. The retrospective nature of the interviews means that participants' accounts are based on memories which, especially given their emotional content, are potentially subject to transformation over time. [46,47] The sample was drawn from one urban setting and biased in composition towards older, female participants (possibly reflecting the population of carers in general) and those of White British ethnicity. Lack of access to interpreters meant that we were unable to include non-English speakers. Caution should therefore be exercised in generalising the findings to other groups and contexts.

Future research is needed to explore how interventions might usefully incorporate the themes presented here. Our findings do not imply that these are necessarily issues to be addressed through formal psychological therapy; in fact, they speak to the power of practical support and simple gestures beyond their immediate, tangible effects. However, there may be scope

for structured interventions to address existential issues: psycho-educational initiatives, for example, could help to normalise the struggles and anxieties caregivers may face. It would be valuable for caregivers to play a role in training professionals on how best they can support them.

Healthcare professionals may also find the model presented here helpful in guiding their thinking about relatives' needs during more 'informal' interactions – particularly as these needs may not be voiced by relatives themselves.[13]

Conclusion

Relatives caring at home for a family member with terminal cancer often face complex emotional challenges including unprecedented levels of responsibility; feeling alone in challenging and ambiguous situations; losing the comforts of familiar roles and relationships; and making sense of and managing thoughts and feelings about death. At the same time, caregiving is frequently embraced as highly meaningful, affording moments of intimacy, spiritual significance, and gratitude. For most participants in this study, becoming a caregiver marked a radical departure from everyday life and conferred a unique intensity to decisions, values and interactions. In this context of uncertainty and heightened meaning, professionals' interventions carry great weight. Feeling unsupported can intensify the burden of responsibility and isolation, whereas attentiveness to relatives' needs can have powerful effects in assuaging anxiety, reducing isolation, and enabling relatives to connect with the positive meaningful aspects of caregiving.

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	Somali	Mother
14	Male	38	Bengali	Father-in-law
15	Female	57	White British	Mother

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: Losing a relationship
	2.3: Being held in mind
3. Death	3.1: Knowing but not knowing
	3.2: Repeated confrontations with mortality
	3.3: Thinking about mortality
	3.4: Protecting family members from existential suffering
4. Meaningfulness	4.1: Giving something back
	4.2: Religion
	4.3: Intimacy
	4.4: Acceptance and gratitude

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COMPETING INTERESTS

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