

Exploring how family carers of a person with dementia manage pre-death grief: A mixed methods study

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Abstract

Objectives: Many family carers of a person with dementia experience pre-death grief. We aimed to identify strategies that help carers manage pre-death grief. We hypothesised that emotion and problem focussed styles would be associated with lower, and dysfunctional coping with higher grief intensity.

Methods: Mixed methods observational study using structured and semi-structured interviews with 150 family carers of people with dementia living at home or in a care home. Most participants were female (77%), caring for a parent (48%) or partner/spouse (47%) with mild (25%), moderate (43%) or severe (32%) dementia. They completed the Marwit-Meuser Caregiver Grief Inventory Short Form and the Brief Coping Orientation to Problems Experienced (Brief-COPE) questionnaire. We asked carers to identify strategies used for managing grief. We recorded field notes for 150 interviews and audio-recorded additional interviews with a sub-sample of 16 participants.

Results: Correlations indicated that emotion-oriented coping was associated with lower grief ($R = -0.341$), and dysfunctional coping with higher grief ($R = 0.435$), with a small association with problem-focused strategies ($R = -0.109$), partly supporting our hypothesis. Our qualitative themes broadly match the three Brief-COPE styles. Unhelpful strategies of denial and avoidance align with dysfunctional coping strategies. Psychological strategies (including acceptance and humour) and seeking support were consistent with emotion-focused strategies, but we did not identify a theme relating to problem-focused strategies.

Conclusion: Most carers identified multiple strategies for processing grief. Carers could readily identify supports and services that they found helpful for managing pre-death grief, yet current services appear under-resourced to meet growing demand. ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT03332979) ID: NCT03332979).

KEYWORDS

carers, dementia, grieving, social support

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Key points

- Pre-death grief is common amongst carers of people living with dementia, however, little is known about how they manage and process their grief.
- Most carers in our study were experiencing grief and used multiple strategies for managing their grief. Our findings provide support that in the context of a progressive, chronic condition, carers can find the carer experience rewarding and lead to personal growth, but some will struggle and find their situation futile.
- Carers could readily identify supports and services they found helpful, suggesting that holistic, individualised assessment of the carer's practical and emotional needs could identify key supports that would enable them to feel supported and have the time to consider and process difficult emotions.
- Current bereavement models may underestimate the level of formal counselling and support these carers need. While family and social networks were important, many did not want to burden family and friends and felt that their network could not fully understand their experiences. Formal supports offered an independent avenue for support that was not bound within existing complex relationships. However, current services appear to be under-resourced to meet growing demand.

1 | INTRODUCTION

The number of people living with dementia is doubling every 20 years¹ and it is a common cause of death.^{2,3} Globally, families provide 82 billion hours of support for people with dementia, equivalent to 40 million full time workers.⁴

Grief is common before the death of a friend or relative with dementia. Pre-death grief is defined as the carer's response to '*perceived losses in a valued care recipient. Family caregivers experience a variety of emotions (e.g. sorrow, anger, yearning and acceptance) that can wax and wane over the course of a dementing disease, from diagnosis to the end of life*' (p2203).⁵ Between 47% and 71% of carers of people with dementia experience pre-death grief and 20% experience complicated grief after death.⁶ It occurs due to the lengthy and uncertain disease trajectory; compromised communication between the person with dementia and family and friends; and changes in relationship quality and carer freedom. Higher grief prior to death is associated with complicated grief after death⁷ so emotional support to manage symptoms of grief during care rather than solely after death may be beneficial.⁸

Blandin and Peppin's theoretical model of dementia grief⁹ poses that dementia involves multiple, ongoing and ambiguous losses. Mechanisms such as acceptance can help carers to move through the grief process by acknowledging loss, tolerating difficult feelings and adapting to new life circumstances. Mechanisms such as denial, however, can stall the grief process. The number of losses and need to continuously adapt can reduce someone's capacity to recognise and process loss. Theories around carers' experiences of burden and grief also propose that how a carer appraises their situation and their coping styles can be as important as external factors on carer well-being.^{10,11} Associations between coping strategies and pre- and post-death grief in carers provides evidence for these theories.^{7,12}

Seeking emotional and practical support from family, friends or services is likely to be a key coping strategy carers use to manage grief. A recent systematic review¹³ found that few studies examined

the services that carers of people with dementia use to manage grief and there is currently insufficient evidence regarding interventions for supporting pre-death grief in carers.^{14,15} The public health framework model for bereavement care emphasises that grief is a normal part of life, and most people will adapt to loss through support from their social network. This framework recognises that some people will require additional support such as a support group or volunteer service while a minority (approximately 10%–12%), will require professional support for prolonged grief disorder.¹⁶

While our understanding of pre-death grief is growing, further work is required to understand how carers manage their grief, the internal coping strategies they employ and services they seek, access and find helpful, to inform the development of suitable and timely support services. This mixed methods study aimed to identify strategies that help carers manage pre-death grief. Our first objective was to examine the association between coping styles and pre-death grief intensity. We hypothesised that emotion and problem focussed styles would be associated with lower grief intensity, while dysfunctional coping styles would be associated with higher grief intensity. Our second objective was to describe the strategies and resources that carers identify using to help manage pre-death grief to provide a more descriptive and rich account of how carers identify managing their pre-death grief. This mixed methods study used correlations between validated measures of coping and pre-death grief to examine the first objective and qualitative and descriptive data to explore the second objective.

2 | METHODS

We conducted a cross-sectional mixed methods study using qualitative and quantitative data, obtained from interviews of people caring for someone with a diagnosis of dementia. Further details of the study have been published.¹⁷

2.1 | Recruitment

We recruited participants living in England and Wales via the Join Dementia Research online database, via newsletters from the UK Alzheimer's Society and emails to Admiral Nurses (specialist dementia care nurses) via the charity Dementia UK. We recruited through nine health services in London ($n = 4$), South Eastern England ($n = 3$), Northern England ($n = 1$) and Wales ($n = 1$) who promoted the study via memory services and community mental health teams.

2.2 | Data collection

Interviews were conducted between January 2018 and January 2019. After referral to the study, we discussed the study with potential participants on the phone and arranged a time for a face-to-face interview at their home or a place of their choice (e.g. café or university offices). Both interviewers had experience working with people with dementia and had completed the Clinical Dementia Rating (CDR)¹⁸ training (KM, SC). We administered CDR questions with the participant carer to determine dementia severity. We calculated the Townsend Deprivation Index using the participant's postal code and the website: <http://imd-by-postcode.opendatacommunities.org>. This enables categorisation in deciles from 1 = most deprived to 10 = least deprived.

2.3 | Data collection for objective 1

Participants completed the 18-item Marwit-Meuser Caregiver Grief Inventory Short Form (MMCGI-SF).¹⁹ Items are rated on a 5-point Likert scale with a score range from 18 to 90. Higher scores indicate higher grief severity. They also completed the Brief Coping Orientation to Problems Experienced (Brief-COPE) a 28-item tool that measures coping styles.²⁰ Responses are on a 4-point Likert scale with a higher score indicating a higher use of that coping style. We used the composite subscales including: emotion-focused, problem-focused, and dysfunctional coping strategies.²¹ As the subscales have a different number of items, we used the average score of the items so that possible scores ranged from 1–4 for all three subscales.

2.4 | Data collection for objective 2

We asked carers whether they felt they were grieving the person with dementia, how they were coping with this grief, and whether they felt their family and friends recognised they were grieving. We asked if they had accessed any of the following support to help manage grief: family and friends, carer support groups, information, General Practitioner (GP), counselling services (private or NHS) or other supports. We took written notes to capture their responses including additional comments they added to the structured-

response questions. In writing notes we tried to retain key words and phrases used by participants to maintain authenticity.

We invited a sub-sample of these carers to take part in an additional audio-recorded qualitative interview about their experiences as a carer. We used purposive sampling to include carers representing different relationships (spouse, child or other), dementia severities (mild, moderate or severe) and genders. This mix was considered important for the qualitative analysis to enable a diversity of views from different demographic groups shown to experience grief differently. The MMCGI-SF was based on a theoretical model²² that explains that grief experiences differ based on dementia severity and relationship type. This interview expanded on the structured interview to explore grief and grief strategies in more detail including how carers recognised and experienced their grief and how it had altered over time.

2.5 | Analysis

We entered all structured data into SPSS Version 21 for analyses. We used descriptive statistics to describe the sample characteristics.

2.6 | Analysis for objective 1

We used Pearson R correlations to test the hypothesis that emotion and problem focussed styles would be associated with lower grief intensity, while dysfunctional coping styles would be associated with higher grief intensity. We used the total score of the MMCGI-SF to measure pre-death grief intensity and the three subscales of the Brief-COPE for the three coping styles. We considered an effect size of 0.1 as small, 0.3 as medium and 0.5 as large.²³

2.7 | Analysis for objective 2

We used descriptive statistics to describe whether carers reported they were experiencing pre-death grief and to record the supports they identified using. For our qualitative analysis we used an inductive approach identifying themes that arise from the data. We used a critical realist approach aiming to reflect the carer's interpretation of their reality and their views on how they managed pre-death grief. We based our thematic analysis on the six steps described by Braun and Clark.²⁴ For all interviews, the interviewers wrote field notes and typed these up within 24 h, while the interview content was fresh in their mind. Qualitative interviews were audio-recorded and transcribed verbatim. A second researcher checked each transcript for accuracy.

We uploaded field notes and verbatim transcripts to NVivo Version 11 software for thematic analysis. Three researchers, with experience in psychology and gerontology, undertook the analysis; two with limited qualitative analysis experience (SC, EF) supported by one experienced qualitative researcher (KM). This multiple

approach was partly for pragmatic reasons given the large amount of data generated from 150 participants but also to improve trustworthiness in the analysis by incorporating different perspectives from researchers, including the two who had been involved in conducting all interviews. Having multiple researchers enabled reflection and explanation as we had to justify and explain how we identified codes and themes. We began by each independently reading and then coding an interview transcript and three sets of field notes. We then met to discuss similarities and differences in our approach to coding. We then split the notes and interviews between us and continued to code independently with regular meetings to discuss key ideas and themes from the coding process. We grouped specific codes together to form broader themes and continued to meet to establish a final set of themes reflecting strategies for managing grief.

2.8 | Synthesis of data

We completed the qualitative analysis prior to the undertaking the planned quantitative analyses so that the results did not influence our qualitative analysis; and integrated the data at the interpretation stage.

3 | RESULTS

3.1 | Participants

One-hundred and fifty carers participated in the structured interview (Table 1). Sixteen of these carers completed the additional qualitative interview. We achieved our aim of including in these additional interviews a mix of gender (9 females; 7 males); relationship type (caring for a parent = 8; caring for a spouse/partner = 5; caring for 'other' = 3) and dementia severity (mild = 3, moderate = 6 and severe = 7). Carers had a mean age of 63; 77% were female and most cared for their parent (48%) or spouse/partner (47%). Most were of White British ethnicity (87%). Scores on the MMCGI-SF indicate an overall moderate level of grief intensity (mean score 57.6 (SD = 12.8)). On the Brief-COPE, participants most commonly reported using problem-focused strategies, followed by emotion-focused strategies.

3.2 | Objective 1: The relationship between pre-death grief and coping strategies

Higher pre-death grief was associated with using fewer problem-focused and emotion-focused strategies, however, the correlations were small for problem-focused strategies ($R = -0.109$). The correlation was moderate for emotion focussed strategies ($R = -0.341$). Grief scores were most strongly associated with dysfunctional coping strategies indicating that the higher the use of dysfunctional coping strategies the higher the grief ($R = 0.435$).

TABLE 1 Participant characteristics

	Mean (SD)	N (%)
Carer characteristics		
Age	63.0 (12.1)	
Female		116 (77.3)
Spouse/partner		70 (46.7)
Adult child		72 (48.0)
Other relationship (not partner or adult child)		8 (5.3)
Number currently in paid employment		52 (34.7)
Deprivation (percentiles 0–10; 0 = most deprived)	6.6 (2.7)	
Brief COPE: Emotion focussed subscale	2.46 (0.52)	
Brief COPE: Problem focussed subscale	2.72 (0.69)	
Brief COPE: Dysfunctional coping subscale	1.69 (0.37)	
MMCGI-SF: Personal sacrifice subscale	20.5 (5.3)	
MMCGI-SF: Heartfelt sadness subscale	20.6 (5.1)	
MMCGI-SF: Worry and isolation subscale	16.5 (4.7)	
Total MMCGI-SF score	57.6 (12.8)	
Characteristics of the person with dementia		
Age	80.3 (9.7)	
Diagnosed before the age of 65 years		22 (14.7)
Female		82 (54.7)
Living in care home/supported accommodation		41 (27.3)
Mild dementia		38 (25.3)
Moderate dementia		64 (42.7)
Severe dementia		48 (32.0)

Abbreviations: Brief COPE, Brief Coping Orientation to Problems Experienced; MMCGI-SF, Marwit-Meuser Caregiver Grief Inventory Short Form.

3.3 | Objective 2: Grief supports accessed

Table 2 shows responses to questions regarding grief and supports sought for managing grief. Most carers acknowledged they were experiencing grief (59% definitely and 14% probably). Of those who were grieving, 30% reported that they were managing their grief well, 39% had fluctuating grief, 4% were not sure and 5% were not managing very well. Regardless of whether carers identified as grieving, over three quarters sought support from family and friends for their grief. Twenty-two percent of carers who were grieving felt that not all of their family and friends recognised their grief. Eighteen per cent of those who indicated they were not grieving, reported that their family and friends thought they were.

TABLE 2 Carer responses to grief and grief supports

Question	Response options	All participants N = 150; n (%)	
Are you experiencing grief whilst caring?	Definitively yes	88 (59)	
	Possibly yes	21 (14)	
	Not sure	8 (5)	
	No	27 (18)	
	Definitively not	6 (4)	
If experiencing grief, how well do you feel you are managing it?	Managing well	45 (30)	
	Some days good, some are not	58 (39)	
	Not sure	6 (4)	
	Not managing very well	8 (5)	
	Not applicable (not grieving)	33 (22)	
Question	Response options	Grieving ^a N = 117 n (%)	Not grieving N = 33 n (%)
Have you sought support from friends and family for grief?	Yes	94 (80)	19 (76)
	No	23 (20)	6 (24)
Do you think your family and friends recognise that you are grieving?	Yes	75 (65)	6 (18)
	No	25 (22)	1 (3)
	Not sure	16 (14)	2 (7)
	Missing/not relevant	1 (1)	24 (73)
Question	Response options	Grieving ^a N = 117 n (%)	Not grieving N = 31 ^b n (%)
Did you seek any of the following formal supports for grief?	Carer support groups	50 (43)	14 (45)
	NHS counselling	28 (24)	6 (19)
	Private counselling	11 (7)	3 (10)
	Any counselling (NHS and/or private)	36 (31)	9 (29)
	General Practitioner (GP)	56 (48)	8 (24)
	Any professional support (counselling and/or GP)	68 (58)	14 (45)
	Other ^c	94 (80)	21 (64)
	Information about supports	23 (20)	5 (15)
	None	6 (5)	5 (15)

^aincludes all participants who reported definitely, possibly and not sure to the question 'Are you experiencing grief while grieving'.

^bmissing responses for two participants.

^cincludes Admiral Nurse (dementia specialist nurse).

Those who reported they were not grieving, reported a similar level of support seeking outside the informal network as those who were grieving. Eleven of the 150 carers (7%) did not seek any formal support for grief. Just under half of all carers tried support groups. Thirty percent of all carers accessed counselling services (more commonly NHS counselling than private) and 55% accessed professional support including counselling and/or a GP for grief. Other avenues frequently identified included Admiral Nursing (dementia specialist nurses), carer education sessions and online forums.

3.4 | Objective 2: Thematic analysis

We identified three key themes regarding the strategies carers used to manage grief: embracing carer identity, psychological strategies and seeking support (informal and formal). However, while carers identified numerous strategies for managing their loss and grief, often these came with a corresponding 'but', particularly for seeking support. For each theme we identify the obstacles carers identified in employing these strategies. See Table 3 for participant quotes to illustrate the themes.

TABLE 3 Illustrative quotes by theme

Theme	Descriptor	Quote	Participant
Embracing carer identity	Caring role bringing them closer to their relative	'Many parts of our lives have... are now kind of interwoven with dad in a way that wasn't the case before... there's been, you know, positive things that have come out of this... in some ways it's felt like we've had an opportunity to form this new relationship [with dad].'	ID9 transcript, male caring for father with severe dementia
	Feeling pride in providing support and doing a 'good job'	'... in amongst the problems I think it let me feel aware of how much good there still is and you know when my mother had dementia I wasn't living with her so I was never ever able to do as much as she needed... With [my partner] I'm with him practically all the time so I don't have that feeling, that feeling of never being enough and that is a good thing ...yesterday, we had a really good period in the middle of the day where he had a lovely time and we had a lovely time. It seemed like everyone around had a lovely time because of him'.	ID51 transcript, female caring for partner with severe dementia
	Supporting other carers with shared experiences	'Research: Very involved and has been over the last 10 years, good to be doing something. Gives talks to carers at dementia days organised by the council, health and education. Gave one recently to 120 people. [It] doesn't feel personal when [participant] is talking, not emotive. Finds doing this useful. On 15 different committees ... A way of directing her anger at someone other than her husband.'	ID43 notes, female caring for partner with severe dementia.
	Recognising own needs and taking time out to look after self	'It's not good for him if your carer is depressed or angry or not coping. So you owe it to the person you're caring for to keep yourself as fit as you possibly can as well, both emotionally and physically'.	ID84 transcript, female caring for partner with mild dementia
Psychological strategies	Acceptance, perseverance, taking 1 day at a time, being positive and pragmatic and using humour	'Accepting we can't do anything about it, so just manage the situation. Just laugh about it really.'	ID84 transcript, female caring for partner with mild dementia
		'When we started looking after [my brother], he was already into the throws of dementia... If you were to take a negative view, we sort of got him for the worst and last year before he went fully into care but on the flip side I don't see it that way. I look at it positively that I was able to help him for that year... it's not been roses all the way but I've been able to understand it... understanding its progression and the fact that it will progress... you can spend time now productively doing things that you want to do.'	ID50 transcript, male caring for brother with severe dementia
	No longer caring for the same person they had known	'She looks like mum, want her to be [her] mum, searching for mum. In a sense [participant] stopped caring for her as "mum", started to care for another person. Easier to manage.'	ID64 notes, female caring for mother with moderate dementia

TABLE 3 (Continued)

Theme	Descriptor	Quote	Participant
	Feeling like their relative is not the same person	<p>'I've just taken my telephone number out of [my father's] phone, he can't contact me and I know that sounds really mean and I did feel guilty for that. But it's only since I've done these little things like that, that I realise if I'd done this 6 months ago ... I might not have got to the point where I was thinking 'is, is life worth living?' You know, it was awful... I've just given myself some, some freedom, emotional freedom and I feel so much better... I have kind of distanced myself a bit from him'</p> <p>'Finally, the endpoint. It has been many years and he [the participant] has accepted she [wife] is gone, she has been in a care home for some time and he is very well supported by others.'</p>	<p>ID19 transcript, female caring for father with moderate dementia</p> <p>ID32 notes, male caring for wife with severe dementia</p>
	Role reversal	<p>'I think about looking after him in the same way I do about my children. You know there are certain health needs, hygiene needs, personal needs that need to be met. Fed, clothed, watered, warm, safe, well...and it's umm you know he was doing that for me 20 years ago. It's now complete role reversal, and that is my role. My primary role in his life is all of those things'.</p>	<p>ID125 male caring for uncle/guardian with moderate dementia</p>
	Unable to see any positives; situation as futile	<p>'No I don't honestly think there is any real upside. Umm, I mean you have the two extremes of knowing there is something that will get worse over an extended period and something happening suddenly... My first wife died suddenly... she had an aneurism... I'm facing the two extremes and this one is harder obviously. I think also I suffer from having a reasonably vivid imagination so I can visualise stages you know... I mean I genuinely feel at the moment...I hope this isn't me being selfish in some way but I genuinely feel at the moment, from [wife's] standpoint it is a much bigger problem for me than it is for her'.</p>	<p>ID41 transcript, male caring for spouse with mild dementia</p>
Seeking support from informal network	Value of support from a close network of family and friends	<p>"[Participant] described a very supportive social network; wife and some very close friends who he's able to get a lot of emotional support from. He also has three young children which helps massively... Wife a lot. Some close friends that are really great. In some of his more 'grumpier moments' they have taken him out for beers etc. Wouldn't talk to the wider circle, people don't want to hear the negatives... But close friends can share."</p>	<p>ID46 notes, male caring for mother with mild dementia</p>
	Keeping family involved and connected	<p>'Stay close with parents, it's very important both for their support and to help them as well. I have got a strong family, my wife's very good she gives me a gentle prod</p>	<p>ID50 transcript, male caring for brother with severe dementia</p>

(Continues)

TABLE 3 (Continued)

Theme	Descriptor	Quote	Participant
		when I need to. And the boys, because we've kept them in the loop as well, they're able to talk about it... several outlets that you know if you need to talk about something and there's somebody there immediately, rather than if you had just a single outlet...'	
	Needing to talk to people who understood their situation	'[Participant has] one friend she can be honest with... Other friends say 'he's taking medication, he will get better'. People don't understand. On a good day [participant] can reflect they are coming from a kind place, on other days she wants to explode. Speak to children but always feels she can't say everything to them.'	ID102 notes, female caring for partner with mild dementia
	Not wanting to burden family and friends	'I am just overwhelmed by this feeling of loss and grief and sadness and I've got no one to talk to about it. I don't want to depress my friends... my closest friends had had some traumatic things in their life so I didn't want to overburden them with... with my problems as well. I need someone to talk to. That's all I wanted was someone to talk to.'	ID2 transcript, female caring for mother with severe dementia
		'I don't like to discuss it with the children because, we've got three children, but they've all got young children themselves and I don't think it's fair'.	ID84 transcript, female caring for partner with mild dementia
	Previous poor relationships as impacting grief and support	'When I was growing up, his relationship with my mum was... he was controlling, very controlling... I still remember that so vividly that I don't want to give in to him. He'll say 'aren't you coming to see me? Aren't you coming to see me?'...I wish I was strong enough to say 'no, I'm not coming to see you today'... She wouldn't want me to be carrying that, but I do.'	ID19 transcript, female caring for father with moderate dementia
Seeking support from formal services	Professional counsellors provided a non-judgemental/independent outlet to social network	'[Participant] has had about 10 1:1 sessions with a psychologist... it has been very helpful and they are open to provide more sessions if needed. It is helpful being able to talk to someone who isn't close family/friends and for the psychologist to tell her that everything is normal... there isn't one thing she has said that the psychologist hasn't heard before from a carer.'	ID129 notes, female caring for partner with moderate dementia
	Carer support groups not always helpful	'Carer support groups: Left [her] so depressed hearing other stories. Was going home a wreck. Think it might be useful for people who need to off load but that's not [her] personality'	ID87 notes, female caring for mother with severe dementia
	Service failing to respond adequately to carer's emotional needs	'[Participant] feels she is not able to access things like carer support groups because they are too far away... They have yearly visits from the memory clinic, progression check. Find it difficult to talk to them in front of her husband... Has said she feels depressed and spoke to her GP about this	ID131 notes, female caring for husband with moderate dementia

TABLE 3 (Continued)

Theme	Descriptor	Quote	Participant
		but they didn't comment or respond... This, as well as other negative experiences with health care professionals around other health issues has put her off going back to the GP. Felt that there wasn't really anything anyone could do anyway... She has fleeting thoughts of stopping taking her medication and seeing what happens... feels this is a normal thought to have given their circumstances.'	

Abbreviation: GP, General Practitioner

3.5 | Embracing carer identity

This theme encompasses the myriad ways that carers found positive outcomes of their difficult situation. Subthemes included: celebrating caring for their relative with dementia, finding value in supporting other people including carers, and recognising their caring role and the need to address their own personal needs through support, respite and enjoyable activities. These strategies do not closely align with subscales of the Brief-COPE.

Some identified positive aspects of being able to reciprocate care to a loved one who may have supported and cared for them in the past. They spoke of the benefits of still being able to share precious time with the person with dementia and recognised their inherent value, despite the impact of dementia and gradual losses. Some found the caring role had brought them closer to their relative with dementia and had highlighted characteristics in the person with dementia that they had not noticed before.

One husband talked about now understanding all the work his wife had managed with maintaining the house and cooking throughout their marriage. Some described how caring had not been as difficult as they had expected or that stresses had reduced over time as support from services increased or the person moved into a care home. This sub-theme also incorporated feelings of pride in being able to provide support and feeling you were doing a good job and developing skills through the caring role.

Finding value in supporting others involved sharing experiences to educate and support other carers, for example, at carer support groups, as well as via research studies. Others found meaning through becoming a Dementia Friends Champion, an initiative of the Alzheimer's Society to train others to learn about dementia. These roles also provided a means of redirecting frustrations and expressing emotions.

Many described the importance of recognising their own needs and taking time out to look after themselves, such as meditation and gardening. Sometimes this was expressed as contributing to guilt or feeling selfish, but it was also considered a necessity in some situations to enable the carer to continue providing care. Some carers, however, struggled to find any value in the caring role, including

those who felt forced into a caring role that stifled their identify and life roles. Time for self was also hampered when carers were looking after someone with high care needs.

3.6 | Psychological strategies

Acceptance, perseverance, taking 1 day at a time, being positive and pragmatic and using humour were all strategies carers used to change their outlook on their situation to make it manageable. These were consistent with the emotion-focused strategies on the Brief-COPE which were associated with lower levels of grief.

In many carers' narratives, there was a sense that they were no longer caring for the same person they had known and loved for many years. An acknowledgement that this was a different relationship sometimes meant that the parameters of relationships needed to be renegotiated. Some carers described accepting that the loved one was no longer here and that while they would care for the welfare of this 'new' person, they would also emotionally detach and grieve the person who they felt was gone. Some spouses felt conflicted when starting new partner relationships in this context but justified that their spouse was no longer their partner. Those caring for a parent often described the role reversal experienced where the parent became dependent on them for care. Some described accepting their role as a carer or the way their relative behaved, while others found it sad and frustrating.

Many carers, however, failed to see positives in their situation and described a sense of futility and that things would not improve. There was evidence of denial, avoidance and self-blame, reflecting the dysfunctional coping strategies on the Brief-COPE which were associated with higher pre-death grief in our quantitative analysis.

3.7 | Seeking support

Most carers discussed the need to build or draw on others for emotional support and we distinguish here between informal networks of friends and family with more formal services through health

and social care. Seeking emotional support is a component of emotion-focused coping strategies on the Brief-COPE, which we found were associated with lower levels of grief.

3.7.1 | Seeking support from informal network

Carers often described a small network of trusted people who were best able to support them emotionally. Many tried to involve their children in caring so that family relationships could be maintained and strengthened. Many carers felt that only others caring for someone with dementia could understand what they were going through. This further increased the sense of futility in talking to others who had not been a carer.

A barrier to seeking support from family and friends was not wanting to be a burden or sounding like a 'broken record'. Previous poor relationships with other family members prevented help seeking and exacerbated emotional distress and frustration. Family and friends who withdrew from the person with dementia and/or the carer, or who disagreed with the carer's approach to care disappointed and angered carers. These experiences further strengthened the need for establishing a reliable support network. However, a previous poor relationship with the person with dementia also created a complex interplay of mixed emotions.

3.7.2 | Seeking support from formal services

Some carers reported that they were no longer grieving because they accessed formal counselling in the past which had helped them process their grief. Some spouses found it difficult talking about intimate loss and grief with their own children and felt that they should protect their children rather than rely on them for support. The support of a professional counsellor provided a non-judgemental outlet.

Carer support groups offered an opportunity for talking about experiences with other carers who were going through similar experiences. Some regularly attended carer support groups, finding them beneficial, however, others attended one or two sessions finding them unhelpful. Some described additional emotional burden of hearing other carers' stories and feeling compelled to provide empathy and support to them. Many had attended and subsequently withdrawn from carer support groups for these reasons.

Carers knew that there were financial pressures on the health and social care system in the UK. Many reported long waiting times, helpful services being cut and services that were difficult to find or too bureaucratic to access. A lack of staff continuity was an obstacle for emotional support where building rapport was crucial. For example, one carer described that they could no longer access their trainee counsellor after the counsellor became qualified. Some described how local councils refused to assess their needs if they were able to self-fund their services and others reported healthcare professionals failing to respond to help seeking.

4 | DISCUSSION

Our findings bring to light a broad range of strategies carers use to manage and process pre-death grief while caring for someone with dementia. It combines data from a large sample of carers incorporating first hand experiences combined with data from validated self-report questionnaires. We found some support for our hypothesis with higher pre-death grief intensity being moderately associated with using dysfunctional coping strategies and using fewer emotion-focused strategies. The association with problem-focused strategies was low.

We identified many approaches to managing pre-death grief that we broadly grouped as embracing carer identity, using psychological strategies (such as acceptance and humour) and seeking support through formal and informal avenues. However, we also found many obstacles to using these strategies such as barriers to accessing services, difficulty finding the right person to provide support, being too overwhelmed or busy to address grief or feeling that their situation was hopeless and there was no way of managing their grief and loss.

Our qualitative themes broadly match the three Brief-COPE styles. Our negative strategies of denial and avoidance align with dysfunctional coping strategies. Two of our themes: psychological strategies including acceptance and humour, and seeking support; have close alignment with the emotion-focused coping strategy. However, we did not identify a theme relating to problem-focused strategies. Our study adds to the evidence that emotion-focused coping strategies are more connected with mental wellbeing than problem-focused strategies²⁵ and therefore helping carers develop emotion-focused strategies may be helpful. The problem-focused approach reflects a pro-active approach to solving problems and may be useful for some aspects of caring, such as getting more assistance in day-to-day tasks. However, it may not offer a benefit for grief where acceptance and adaptation to inevitable loss may provide greater relief from distress.

Our first theme of embracing the carer identity, does not appear to relate so closely with the Brief-COPE styles, although could be considered a form of positive reframing. Reflecting on grief processing theories may help explain why some of the coping styles were more useful in the context of processing grief and loss. The Dual Process Model (DPM) of coping with bereavement²⁶ suggests a cycle rather than stages of grief where people oscillate between confronting the loss (loss orientation) and compartmentalizing it so that the mourner can attend to life changes necessitated by the death and need for new roles (restoration orientation). While the DPM was developed in the context of grief after death, it highlights the importance of having a balance between difficult emotional processing (i.e. our psychological strategies and seeking emotional support themes) with taking a break from emotional and practical tasks of caring for someone with dementia (i.e. our embracing carer identity theme). Our finding that 39% of participants described the fluctuating nature of grief and how some days they could manage while on other days they struggled, also reflects the oscillating nature of grief work described by the DPM.

Our 'embracing the carer identity' theme also highlights numerous rewards from caring which resonates with previous work which identified that dealing with challenges as a carer and grief and loss can provide opportunities for personal growth and development.¹² There has been criticism that research on family carers has focussed too much on the negative consequences of caring, failing to acknowledge rewarding aspects.²⁷ Some carers in our study, however, failed to identify any positive aspects and instead showed signs of depression and suicidal ideation. Dysfunctional coping and its relationship to grief were identified in both quantitative and qualitative data. These intense feelings were evident for those caring for someone in the early stages of dementia, through to the advanced stages. Some carers also indicated they were not grieving, yet reported that their family felt they were grieving, which may suggest denial of grief. While this may create a protective barrier, it may also block acknowledgement and acceptance of grief as per Blandin and Peppin's dementia grief framework.⁹

Acceptance was an important coping mechanism for many carers in our study and has been previously identified.²⁸ A recent feasibility study has shown promising results for using Acceptance and Commitment Therapy for carers of people with dementia for reducing anxiety, depression and burden²⁹ yet most carer interventions do not include the concept of pre-death grief.³⁰ Our findings highlight that supporting carers requires understanding and acknowledging the complexity of the grieving process as carers adapt to fundamental changes in their significant relationships.

Health literacy may also be an influencing factor. We previously reported from this study a relationship between health literacy and knowledge of dementia.³¹ We also found that those who had a higher knowledge of dementia reported lower levels of 'heartfelt sadness' one of the subscales of the MMCGI.¹⁷ Health literacy, therefore, may also be a contributing factor that we need to consider when developing interventions.

4.1 | Implications

The public health model for grief support appears to underestimate the extent of formal counselling and peer support that carers require to manage pre-death grief in the context of caring for someone with dementia. While this model suggests 10%–12% require formal counselling, in our study 30% of participants sought formal counselling, 48% approached their GP and 43% accessed carer support groups. While family and social networks were extremely important for providing support, these alone were often insufficient for carers to process grief. Many did not want to burden family and friends, felt that their network could not fully understand their experiences and avoided family where there was conflict. Formal avenues of support offered an independent avenue for support that was not bound within existing complex relationships.

Our finding that many carers were coping well with grief is also a promising finding. It may be encouraging for carers who are new to caring, to learn that while dementia is a progressive condition, the

experience of caring is not inevitably a decline. Some carers found that their ability to adapt, learn, grow and find access to appropriate services contributed to easing the burden and grief of caring over time. While the transition to a care home can trigger grief, it also reduced the burden for some carers, providing them space to grieve their losses. There is growing evidence that family carers, particularly spouses, require additional support during this transition.³² There is an opportunity to learn more from these carers to understand how they manage to adapt to the caring role.

The encouraging finding is that carers could readily identify supports and services that they find helpful. An holistic, individualised assessment of the carer's practical and emotional needs could identify key supports that would enable them to feel supported and have the time to consider and process difficult emotions. Unfortunately, growing pressures on mental health and social care systems mean that the vital supports these carers need may not be available in a timely manner and may discourage help seeking. Given that family carers provide the bulk of support to the growing number of people living with dementia, not routinely providing adequate support to these carers is short sighted. In the context of the UK, our findings that local authorities are not carrying out carers' needs assessments for those perceived to be able to fund these for themselves is a transgression of the UK Care Act (2014).

4.2 | Study limitations

Participants were recruited through various clinical and non-clinical avenues but were not a representative sample. Our sample provided a reasonable representation of the diversity of carers in terms of age, gender, employment status, relationship type, rurality and deprivation,¹⁷ however, there was little cultural diversity in our sample. There are likely to be differences in cultural expectations around the caring role as well as how people discuss, acknowledge and respond to grief and loss, indicating a need for further research in different cultural contexts. Carers in denial of grief or who do not feel it is relevant to them may have been less likely to participate.

We used carer self-report and the MMCGI-SF to assess pre-death grief, however we did not include a clinical assessment of grief to verify grief severity. There may also be limitations to determining dementia severity by relying only on the carer's report, however, it was not feasible within this study to undertake further clinical evaluation. While use of written notes enabled us to capture rich data for a large number of participants, there are limitations to this approach. For example, some points may have been missed due to the speed of information being presented and the need to summarise in a written format. We are unable to determine whether the strategies carers identified were useful or detrimental to processing grief. We asked carers to report whether they accessed formal supports for grief such as counselling, GP, carer support groups at any time during the caring journey, however, we did not assess the level of use, timing of these services or satisfaction. Correlational

research is also limited; we are unable to conclude whether coping strategies influenced grief or grief influenced coping strategies.

The nuances of service changes and support seeking over time, therefore, have not been captured in this study. Longitudinal studies may be useful to understand how supports and grief evolve and impact each other over time. Qualitatively there was evidence of the changing and dynamic nature of caring and grief. For some, grief intensified as time progressed and losses accumulated, for others, however, the passage of time helped heal their grief allowing them to process and accept losses and prepare for their relative's death.

This study was undertaken before the COVID-19 pandemic and so many of the strategies identified by carers in this study may now have further barriers to implementation. Carer support groups may have moved online or been cancelled altogether and access to support networks restricted. Evidence of carers becoming more reluctant to seek support on highly pressured health systems is emerging³³ and is likely to mean that carers will become further isolated in adapting to grief and loss.

5 | CONCLUSION

Most carers in our study were experiencing grief and used multiple strategies for processing and managing their grief. Our findings provide support that in the context of a progressive, chronic condition, carers can find the experience rewarding and lead to personal growth, but some will struggle and find their situation futile. Current bereavement models may underestimate the level of formal counselling and support these carers need and current services appear to be under-resourced to meet growing demand. Carers provide the bulk of care for people living with dementia and have a right to access appropriate supports to maintain care and support their mental health.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

We obtained approval through the London - South East Research Ethics Committee (Reference 17/LO/1881) and the University College London Research Ethics Committee (Reference 11755/001). The Health Research Authority (Sponsor Reference Number 17/0477) approved the study.

PATIENT CONSENT STATEMENT

All participants provided written informed consent.

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