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Understanding the experiences and psychosocial support needs of caregivers of people with comorbid dementia and cancer

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ABSTRACT

Background: Family carers of people living with comorbid dementia and cancer (CDC) play a vital supportive role, but this may be particularly burdensome and adversely impact their own health and wellbeing.

Objective: To examine the experiences and psychosocial support needs of caregivers of people with CDC.

Methods: A flyer advertising the study was distributed to relevant UK voluntary sector organisations and shared across social media. 13 carers of people with CDC were recruited. In-depth semi-structured interviews were conducted and transcripts were analysed using reflexive thematic analysis, underpinned by an inductive phenomenological approach.

Results: Complex interactions of dementia and cancer resulted in heightened responsibility for carers, who played a crucial role in recognition/management of symptoms, performing difficult cancer-related care, and treatment decision-making that posed difficult ethical challenges. Care-recipients had reduced insight into their cancer diagnosis and prognosis, so carers often carried the emotional burden alone. Responsibilities faced by carers were compounded by a lack of targeted, accessible information/support for CDC. Carers expressed a desire to talk to and learn from others who understand the unique challenges of navigating cancer-related decision-making, treatment and care for people who are also living with dementia.

Conclusions: Cancer alongside dementia presents complex challenges for carers, who desire more cancer-related information and support which is tailored to people living with dementia and their family caregivers.

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Introduction

Owing to population ageing and the associated increase in multimorbidity (Kingston et al., 2018; Office for National Statistics, 2019), a significant number of people are

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living with co-occurring diagnoses of dementia and cancer (CDC). A recent study, using a sample of UK primary care records, found that 7.5% of people aged 75 and over with a cancer diagnosis also had a diagnosis of dementia (Collinson et al., 2022). Moreover, prevalence rates are likely to be higher than those recorded, given that dementia is under-diagnosed and its symptoms may delay or prevent the diagnosis of other conditions (Lang et al., 2017). Owing to its progressive nature and cognitive, functional and behavioural impacts, having dementia increases the complexity and burden of cancer treatment decision-making, poses challenges in practically and emotionally navigating cancer care, and compromises an individual's self-management of symptoms and side effects (Ashley et al., 2021; Griffiths et al., 2020; McWilliams et al., 2018; Surr et al., 2020; 2021). People with CDC are therefore especially likely to rely on support from family carers.

Family carers play a crucial role in facilitating access to cancer care and treatment for people with dementia (Surr et al., 2020). Recent studies demonstrate that carers are often relied upon heavily by both people with CDC and healthcare professionals, for arranging and attending appointments and treatments, recall of medical history and symptoms, practical support with cancer management, treatment decision-making, and cognitive and emotional support (Courtier et al., 2016; McWilliams et al., 2020; Surr et al., 2020; Witham et al., 2018). It is well-documented that family caregiving is associated with adverse health consequences (Bom et al., 2019), and providing care for people with *multiple* chronic conditions, especially when dementia is present, is particularly challenging (Amer Nordin et al., 2019; Price et al., 2020).

Despite this, the experiences of this carer group are particularly under-researched. Existing work has focused predominantly on the cancer care and treatment of the individual with CDC (Ashley et al., 2021; Courtier et al., 2016; Griffiths et al., 2020; McWilliams et al., 2018; 2020; Surr et al., 2020; 2021), with only a few studies to date including a sole carer sample (i.e. not alongside patients or healthcare professionals) (Hynes et al., 2022; Martin et al., 2021; Witham et al., 2018). Moreover, caregiver studies have primarily centred around treatment decision-making experiences (Hynes et al., 2022; Martin et al., 2019; 2021), and no studies to date have examined in-depth carers' own psychosocial support needs and preferences. Indeed, there have been numerous recommendations for future research exploring the needs of this carer group (e.g. Surr et al., 2020; Courtier et al., 2016; Martin et al., 2019). Advancing understanding of the unique challenges faced by this growing carer group and their supportive needs is necessary to inform the development of psychosocial interventions which may improve caregiver burden and health outcomes (Pearlin et al., 1990). This qualitative study aimed to provide an in-depth examination of the experiences and psychosocial support needs of family caregivers of people with CDC.

Method

Participants

Eligibility criteria: (1) providing unpaid care to a person with CDC, currently or within the last five years; (2) aged 18+ years; (3) English-speaker.

Carers were eligible if they had provided unpaid care for someone with CDC within the last 5 years. This enabled the inclusion of people caring for someone with CDC who had recently passed away, and those caring for someone who previously had CDC but were now a cancer survivor, while still ensuring participants could provide an in-depth account of their experience that is relevant to the current health and social care context.

Sampling and recruitment

Participants were recruited using convenience sampling. A flyer was shared on social media, in local newspapers, and via relevant charities and community groups across the UK. Interested carers contacted MP for more information and to arrange an interview.

Data collection

A semi-structured interview topic guide was devised following the procedure described by Smith (2015), focusing on experiences of caring for a person with CDC, carers' challenges and support needs, and experiences of and preferences for support (Appendix 1). This was used flexibly to guide the direction of the interviews, but was adapted and build upon within interviews based on topics raised by individual interviewees. This ensured we obtained relevant data for addressing the research aims while also allowing participants to speak freely and raise unanticipated topics. Participants completed a sociodemographic questionnaire prior to beginning the interview. MP conducted the one-on-one interviews face-to-face or via telephone, depending on participant preference. Interviews were audio-recorded and transcribed verbatim by MP.

Data analysis

Transcripts were analysed using Braun and Clarke's (2006, 2019) reflexive thematic analysis (TA). Though not constrained to a particular theoretical framework, researchers must be transparent about the theoretical and epistemological assumptions informing their approach (Braun & Clarke, 2019). This study adopted an experiential approach, underpinned by a hermeneutic phenomenological position, as it was concerned with gaining an understanding of lived experience and participant-defined meanings (Laverty, 2003). In addition to exploring experiences, we sought to identify carers' psychosocial support needs to inform recommendations for interventions, policy and practice. Therefore, it was important for the analysis to identify commonalities across the dataset, rather than unique features of individual cases, which required a holistic (cross-case) rather than an individual approach. A phenomenological approach to reflexive TA was thus most appropriate for addressing the aims of this study (Braun & Clarke, 2021).

Given that the experiences of caregivers of people with CDC are largely under-researched and their support needs unknown, the analysis sought to provide a detailed description of the entire dataset, rather than an account of one specific aspect of the caregiving experience. The purpose was to highlight predominant themes across the data, to establish an understanding of the shared experiences and support needs of this group, irrespective of sociodemographic characteristics, specific

diagnoses, treatment types and outcomes. Themes were developed inductively and at a semantic level (Braun & Clarke, 2006). See [Appendix 2](#) for a discussion of reflexivity.

The transcripts were first read repeatedly to increase familiarity with the dataset and to identify meaningful units of text relevant to the research aims. Extracts were then collated within provisional codes, which were examined to determine how they may combine to form potential themes. The original dataset and the selected extracts were then revisited to review and refine the initial themes and codes. Final themes and sub-themes were then named and defined. The initial coding process and theme development was conducted by MP, though coded transcripts and in-progress themes were discussed and refined iteratively among the research team (MP, CS, BG, LA) throughout the different stages of the analytic process.

Ethics

The study received approval from the Leeds Beckett University Psychology Group Research Ethics Committee (January, 2017). Participants provided written informed consent. Illustrative quotes have been anonymised.

Key findings

Participants

Thirteen caregivers participated; sample characteristics are summarised in [Table 1](#).

Data collection

Interviews were conducted February 2017—April 2018, predominantly face-to-face ($n=9$), and lasted on average 75 minutes (range = 57–103 minutes).

Thematic analysis

Four themes and associated sub-themes were developed from the dataset concerning the challenges and psychosocial support needs of carers of people with CDC ([Figure 1](#)).

Theme 1 - Heightened responsibility: 'It all hangs on me'

The combination of extensive care responsibilities required for the management of cancer and the impact of dementia on care-recipients' ability to self-manage such care engendered a sense of heightened responsibility for caregivers.

1.1 Becoming detectives with few clues

Carers commonly reported that care-recipients had an impaired capacity to communicate cancer-related symptoms or side effects they were experiencing. Resultingly, carers stressed their vital role in monitoring and recognising symptoms in advocacy of their relatives, which was a particular source of anxiety and pressure:

Table 1. Participant characteristics (N = 13).

Age, years	
Mean (Range)	57.08 (26–76)
Gender	
Female	10 (76.9%)
Male	3 (23.1%)
Ethnicity	
White British	12 (92.3%)
Eastern European	1 (7.7%)
Relationship to care-recipient	
Spouse/partner	5 (38.5%)
Adult child	5 (38.5%)
Grandchild	2 (15.4%)
Child-in-law	1 (7.7%)
Education	
Degree level qualification or above	7 (53.8%)
Other educational/vocational qualification below degree level	6 (46.2%)
No qualifications	0
Residing with care-recipient	
Yes	6 (46.2%)
No	7 (53.8%)
Current employment	
Full-time	2 (15.4%)
Part-time	3 (23.1%)
Not regular hours	3 (23.1%)
None	5 (38.5%)
Hours of care per week	
0–9 hours	1 (7.7%)
10–19 hours	4 (30.8%)
20–39 hours	3 (23.1%)
40–59 hours	1 (7.7%)
60–99 hours	1 (7.7%)
100+ hours	3 (23.1%)
Care-recipient dementia diagnosis	
Vascular dementia	2 (15.4%)
Alzheimer’s Disease	5 (38.5%)
Frontotemporal dementia	1 (7.7%)
Mixed dementia	2 (15.4%)
Parkinson’s disease dementia	1 (7.7%)
Cortical basal disease with dementia	1 (7.7%)
Not specified	1 (7.7%)
Care-recipient cancer diagnosis	
Bowel	5 (38.5%)
Ovarian	1 (7.7%)
Breast	2 (15.4%)
Skin	2 (15.4%)
Laryngeal	1 (7.7%)
Prostate	1 (7.7%)
Lung	1 (7.7%)

Living with dementia and cancer, is a very different issue from living with say cancer and a heart condition. The difficulty when somebody has short-term memory loss is that they can’t help clinicians to understand [their symptoms], and that’s where the carer comes in.

(08_wife-caregiver)

Participants described needing to be ‘be alert’ to warning signs and playing a ‘detective’ role in watching for and monitoring symptoms. However, there was a shared sense of uncertainty about what they should be looking for, and a lack of confidence in their ability to recognise when something was wrong. This was exacerbated by a lack of CDC-specific information:

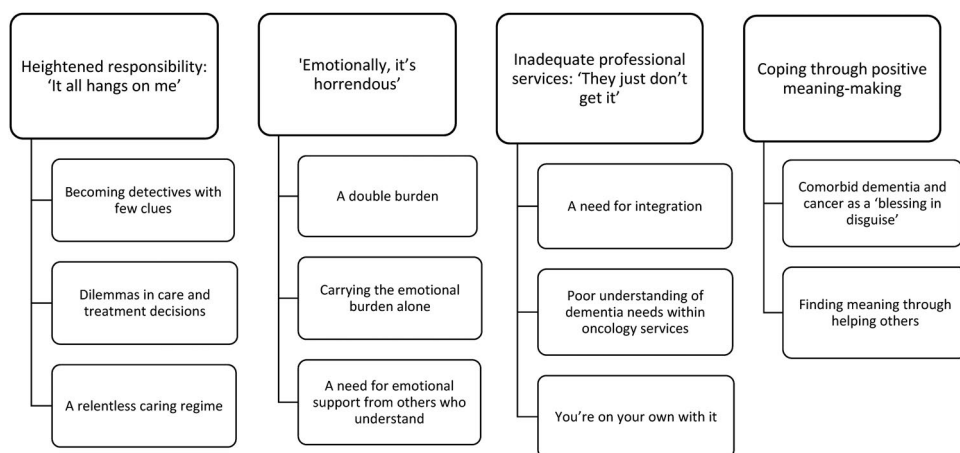


Figure 1. Key themes and sub-themes identified concerning the psychosocial challenges and support needs of caregivers of people with CDC.

Nobody seems to have much to say about Alzheimer's and cancer. That was what I found. I mean I was googling it, to try and find things out but there's nothing.

(09_daughter-caregiver)

Consequently, carers commonly reported feeling unprepared for complications that arose, and failure to recognise a particular symptom or complication elicited feelings of guilt and blame:

I mean with the bowel cancer, I never expected that to be honest because he'd had no problems. So I wasn't aware [...] I don't know whether I could have done anything, was there anything I should have known but didn't?

(04_wife-caregiver)

Participants expressed a shared desire to learn from others with experience of CDC. Some wanted to talk to health or other care professionals with an understanding of both conditions, while others emphasised the potential value of learning from other carers of people with CDC:

I know everybody won't be the same, but if you know somebody who can say 'she does this and she does that', you might think 'oh yeah my mum does that too', and that might help a little bit as to what you're looking for.

(02_daughter-caregiver)

1.2 Dilemmas in care and treatment decisions

All participants reported that dementia impaired their relative's understanding of their cancer diagnosis. Consequently, carers voiced heightened responsibility in cancer-related decision-making.

Many carers were faced with the emotional dilemma of deciding on behalf of their relative whether to pursue curative cancer treatment or palliative care. Carers positioned themselves as advocates for their relative, and felt pressure to make decisions as their relatives would, but what their relatives would want was not always known:

Now that wouldn't be my choice [to refuse treatment], but I feel I have to act as though she would want me to act.

(01_husband-caregiver)

With the dementia it's more difficult to know what she would say, my guess is that she would say 'I don't want all this.'

(13_daughter-caregiver)

Participants struggled with the weight of responsibility of making treatment-related decisions. Many described feeling accountable for "putting them through" treatments and operations which had caused distress and confusion for care-recipients. Others who chose not to pursue cancer treatment expressed guilt in "letting them die". Carers wanted approval that they were making the 'right' decision:

It took an awful long time and that's where we really could've done with some support because my mum wasn't able, she didn't have capacity at this point to tell us what she wanted, and obviously you don't want to sign a death warrant for your mum.

(02_daughter-caregiver)

Advice from healthcare professionals and understanding the potential implications of treatments and their interactions with their relative's dementia was highly valued in aiding the decision-making process. Professional input helped to relieve the accountability felt by carers, and provided a sense of comfort and reassurance around decisions made:

We deliberated, we got them back again and had another talk to them and basically it was the anaesthetist that really made my mind up. They know their business, I don't.

(02_daughter-caregiver)

1.3 A relentless caring regime

Typical of dementia-caregiving, most carers described their increasing need to assist their relatives with activities of daily living, including bathing, dressing and toileting. However, care-recipients' comorbid cancer diagnoses brought many additional physical care needs.

Carers voiced that their relatives' increasing care needs were coupled with a reduced ability to understand and self-manage the complexity of their own cancer care. Consequently, carers' responsibility for such care was heightened:

And when your husband has dementia as well as cancer, I think what makes it difficult is you're not simply there for support, you have to direct everything. They can't help with their own care.

(12_wife-caregiver)

Carers voiced feeling overwhelmed by managing both dementia and cancer, and highlighted how the demands of one condition could detract care from the other:

I was so busy sort of looking after him that I missed the last two skin cancers [...] I'm supposed to sort of check but I just got so wrapped up in caring for the dementia that I just forgot to check.

(06_daughter-caregiver)

We never ever acted on the dementia element of it because we were so utterly wrapped up in the bowel cancer. 'Cause he [the doctor] said there's a drug we can put her on, Rivastigmine I think it's called which is an Alzheimer's drug to inhibit the development of it. But we were up to our ears in bowel cancer.

(01_husband-caregiver)

Carers voiced that their relatives sometimes found it difficult to understand what was happening during cancer appointments, investigations and treatments, and could become confused and upset. Consequently, carers played a vital role in pacifying care-recipients and helping them to co-operate with treatments or investigations, which could be emotionally draining:

It was really difficult to get her to go to the appointments and getting her to understand what was going on. That was quite difficult, it was quite emotionally draining on me, quite stressful, knowing that she didn't want to go anywhere but she had to go to the hospital.

(11_granddaughter-caregiver)

Whenever she's put in a strange environment, she doesn't know where she is and I think that's frightening [for her], and then she goes off on one and I'm trying to explain what's happening and comfort her.

(01_husband-caregiver)

Several carers emphasised how their relative's dementia diagnosis increased their vulnerability following operations and treatments, placing additional demands on carers to monitor them throughout recovery. For example, carers described their relatives picking at malignant lesions and pulling out stitches and a laryngectomy valve, meaning care-recipients required constant observation:

It would've been very easy for him to physically hurt himself, because he was so vulnerable physically with all the stitches and the wounds and all that kind of thing. And that really adds a layer of stress that I just can't, I was afraid to close my eyes, you know. Yeah, that was awful. It's awful, and terrifying. I caught him once picking the staples out of his stomach.

(12_wife-caregiver)

Moreover, participants frequently had responsibility for performing surgery aftercare, administering medications, stoma care, and managing symptoms and side effects. However, these were often met with resistance, and carers could struggle with feelings of anger and frustration towards their relatives who were unaware of the seriousness of their condition:

I was tryna do his treatment as well as fending off his arm swinging at me when we needed to do it, and just tryna keep him sat down whilst you did it.

(07_son-in-law-caregiver)

He just wouldn't take it. And I'd taken photographs of him and I'd put them at the side of his bed to show him in hospital to try to explain how poorly he'd been and how

serious it was, but you just could not, it was a disaster. It was really really challenging. And you know, you want to lose your temper with them, he was singing at me and it was just awful.

(09_daughter-caregiver)

Despite the difficulties carers faced performing such care, many felt it was their duty, and were reluctant to accept help from formal care services, believing it would cause more distress for care-recipients:

I did everything. I emptied the ileostomy bag, I cleaned it, I changed it, I took the bag off and disposed of it and put a new bag on. The nurse showed me how to do everything like that because he got to a stage where he didn't want anyone else to touch him, so that became hard for me, and that's the reason why I didn't get carers in.

(03_wife-caregiver)

Theme 2 - 'Emotionally, it's horrendous'

Carers emphasised that the combination of cancer and dementia had a unique and challenging impact on their emotional wellbeing.

2.1 A double burden

Carers voiced that the combination of cancer and dementia was more difficult to cope with than one condition, and "made everything twice as bad" (06_daughter-caregiver). They reported feeling all-consumed by the emotional burden of both diagnoses, particularly owing to their differing nature, emphasising the amalgamation of physical deterioration due to their relative's cancer and cognitive deterioration due to their dementia:

I think it was more upsetting when it's both [cancer and dementia] 'cause you knew she couldn't go out anymore [cancer affected mobility] and she weren't the same person as well.

(10_granddaughter-caregiver)

With the pain of the cancer also and the deterioration that's having physically, while mental health is going on as well, it's like a double sword.

(02_daughter-caregiver)

Participants expressed the struggle they faced in seeing their relative suffering as a result of progressing cancer and/or treatment. Though the co-occurring dementia presented an additional component to their mental anguish, as care-recipients' impaired understanding of their suffering engendered feelings of guilt and helplessness for carers:

And also seeing him suffer, and not being able to help it or even to explain it in a way that he could truly understand or retain the knowledge, he might understand it in the moment but then he would forget. And that's very hard to see.

(12_wife-caregiver)

But both dementia and cancer, you are watching them just die, and it's torture, I'm gonna cry in a minute, it's absolutely torture.

(02_daughter-caregiver)

2.2 Carrying the emotional burden alone

Carers reported that their relatives frequently forgot about their cancer diagnosis, or had a reduced understanding of its implications, particularly as their dementia progressed. Some participants noted instances where attempting to talk to their relative about their diagnosis and/or prognosis had caused upset; others had decided from the outset not to disclose the cancer diagnosis to their relative to protect them from distress or because they believed they would not fully understand:

It just would've been cruel.

(09_daughter-caregiver)

Carers voiced wanting to "keep them happy" and "put their mind at rest". However, caring for a person who did not always understand they were ill was isolating for carers:

My feeling was that because cancer is mechanical, if your partner has all their marbles, you can fight it together as a team. When your partner has dementia, you're fighting it alone. You really are.

(12_wife-caregiver)

Many reported their relatives were 'oblivious' to their declining health, and as a result, there was a sense that the emotional burden was subsumed entirely by the carers:

And you'll find your friends as well, they go 'How's your dad?' and I go 'My dad's fine! He's in a world of his own, he's got *no* idea. *Me* however, I'm not fine, I'm on the verge of a nervous breakdown, but nobody ever bothers asking about me.'

(06_daughter-caregiver)

2.3 A need for emotional support from others who understand

The emotional toll of cancer and dementia had a significant impact on carers' psychological wellbeing. As carers often reported feeling unable to talk openly to care-recipients about their condition, the need to offload was commonly expressed.

Some participants expressed a desire for their relative to pass away from their cancer, though there was a sense of perceived stigma in feeling this way, and they felt friends were unable to empathise with their situation:

I had a meltdown last week and I just said 'Gosh I wish sometimes my dad would just pass away' 'Oh you don't mean that', I said 'Have you looked after him lately?' 'Well no, but you don't mean it' 'Yes I do mean it, right at this very moment I do mean it' 'Oh you'll be fine' you know, it's like *no*, I won't be fine.

(06_daughter-caregiver)

Participants also conveyed a desire to connect with other carers who understand the unique experience of caring for a person with CDC. They voiced a need for a "safe place" where they could speak honestly to others without judgement:

That's the most important thing, you need to have people who you can talk to honestly and in a way that if anybody were listening they would be horrified, but that kind of humour gets you through.

(13_daughter-caregiver)

Despite this, some carers reported difficulty attending peer support groups due to the demands of caregiving, inability to arrange replacement care or competing responsibilities. For those who could, peer support groups had a positive impact on wellbeing, and participants expressed that it was relieving knowing they are not alone. However, several participants noted that there were no support groups specific to the challenges of cancer alongside dementia:

But there are certain times when it needs to be a specific group, to understand what the other person is going through.

(06_daughter-caregiver)

I didn't meet anyone else caring for someone with both cancer and dementia, that's the problem. It would be wonderful to bring them together.

(08_wife-caregiver)

Theme 3 - Inadequate professional services: 'They just don't get it'

The challenges faced by carers were exacerbated by a health and social care system not equipped for dealing with the challenges posed by CDC.

3.1 A need for integration

The combination of cancer and dementia involved a range of complex interactions and created additional and/or differing responsibilities and challenges for carers. However, in contrast to how CDC was experienced by the carers, participants voiced that care-recipients' diagnoses were treated in isolation:

For the individual and for the family, the two are *totally* intertwined. For the care system, secondary care system but the GP as well, they're completely separate. And they just don't get it (laughs). They simply do not understand that having one condition materially affects the other.

(13_daughter-caregiver)

Carers reported a lack of adequate guidance for providing physical cancer-related care for a person with dementia; a lack of suitable residential care facilities that could manage both cancer and dementia care needs; and a lack of co-ordination and communication between specialists:

Nobody involved with the dementia has *ever* mentioned the cancer, and nobody involved with the cancer has ever mentioned the dementia.

(13_daughter-caregiver)

As a result of poor integration, carers suggested that healthcare professionals failed to understand the complexities of the combination of cancer and dementia. For

instance, one participant voiced her dissatisfaction that a GP had not considered the impact of dementia on her mother's perceived ability to cope with cancer treatment and recovery prior to making a referral to remove cancerous skin lesions. Moreover, many participants described unexpected instances of interactions between treatments or accelerated decline in their relative's dementia symptoms following cancer treatments, which intensified existing emotional and practical burden:

They didn't tell us anything about that that would have an impact, so it was such a shock that she got bad really quickly.

(10_granddaughter-caregiver)

What we didn't know was that this hormone therapy would completely stop the dementia medication working. Within four weeks, Rick was hallucinating, he developed schizophrenia. Life was horrendous.

(08_wife-caregiver)

This left some carers feeling regretful in deciding to pursue treatment for their relatives. Carers emphasised the vital importance of improved integration of secondary care services, and communication between specialists ahead of making cancer treatment decisions:

I think the biggest thing that would make the biggest difference is better integration of secondary care services, so that people within them understood the impact of the dementia on particular cancer treatment. And also the impact of the cancer on the dementia.

(13_daughter-caregiver)

3.2 Poor understanding of dementia needs within oncology services

Numerous carers voiced that oncology staff did not know how to speak to someone living with dementia, expressing frustrations with communication that was alienating and patronising, or instances where staff had spoken directly to the carer instead. Such interactions had led to confusion and distress for care-recipients, and left carers with the difficulty of explaining complicated information about cancer diagnoses and/or treatment following appointments:

I think it just added to her confusion, because the doctors didn't necessarily speak directly to her, they spoke to me, as if she didn't exist, so when we came out of the hospital I'd just be bombarded with question after question after question. There wasn't many staff that I ever came into contact with at the hospital that seemed to know how to communicate with her.

(11_granddaughter-caregiver)

Throughout procedures and treatments for cancer, the familiar presence of the carer was emphasised as vital for care-recipients' wellbeing and co-operation with treatment. However, some participants voiced that this was not always considered by hospital staff. Consequently, it relied on carers to request adaptation of cancer services to the needs of the person with dementia, which could be onerous:

Soon as I arrived I said I've brought Christine she has dementia so I'll need to stay with her. 'Oo I don't know about that...'; I said 'Well we'd be better if I did'. So I kept having to repeat

it, and every time they went and got the next more senior person to talk to me about it. Eventually I had a conversation with the surgeon and he *clearly* didn't like it but sort of said 'Well yes alright, but you'll have to put a gown on.' And they let me do it, but I probably had to say it to five maybe six different people, and not one of them had thought about it.

(13_daughter-caregiver)

Participants reported that staff often failed to consider the impact that dementia had on the care-recipients' understanding and communication, and as a result, did not adequately recognise and treat care-recipients' needs:

He was incapable of providing his own pain relief because of the dementia, and I do remember I'd have to like sneak, you know they have the button you push? And they yelled at me once when they caught me pushing it, saying 'You can't do that!' and I was like 'He doesn't understand! He doesn't understand how to give himself pain relief.'

(12_wife-caregiver)

A sense of mistrust in oncology staff was evident. Participants frequently voiced having to 'check up' on staff in order to meet care-recipients' complex needs, intensifying care burden:

I was watching the clock and phoning them when I figured it was time for the antibiotics and saying 'Can you put them in his mouth and give him a glass of water because he will not know what to do.' I did it a lot, I would phone just to check, and of course that's a nightmare 'cause you know what it's like trying to get through to a busy hospital ward.

(12_wife-caregiver)

3.3 *You're on your own with it*

Carers reported that support was rarely offered to them from health and social care services, and they were often unaware about support that was available. There was a sense of abandonment by services and discontent at being left to cope alone, exacerbating existing feelings of loneliness:

The hospital, like with anything else it was just 'deal with it'.

(04_wife-caregiver)

I've been improvising all along the way, trying to figure it out on my own. It's a very lonely path that's for sure, 100% lonely path.

(12_wife-caregiver)

Carers wanted professionals to better sign-post to existing support, and desired more centralised support encompassing both conditions:

This information may be out there and available but you don't know what to do and you can't because you've got so much on your plate, and you're mentally perhaps not functioning properly, or I wasn't anyway, because you're not getting enough sleep. I mean someone might say 'Oh but there is [help] if you do this this and this' and it's like well errr *one, one point*, that would be my dream.

(12_wife-caregiver)

I think the family need to be sat down and said 'Right he's got cancer *and* he's got dementia, we can either give you everything you need together, or we can give you

the dementia helpline and the Macmillan nurse to look after the cancer' and then it's up to the family how they want it done.

(06_daughter-caregiver)

Theme 4 - Coping through positive meaning-making

Although the experience of caring for a loved one with CDC was expressed by participants as extremely challenging, making sense of both the combination of cancer and dementia and their own caregiving role by deriving positive meaning from the experience was presented as an important factor in coping.

4.1 Comorbid dementia and cancer as 'a blessing in disguise'

Carers struggled to cope with the interactions of cancer and dementia, which gave rise to increasing carer responsibility and emotional challenges. However, carers also voiced an alternative perspective, one that posits the combination of dementia and cancer as positive.

Several carers whose relatives had incurable cancer reflected on how they had reappraised it as a "blessing", accepting it as a preferable outcome to an uncertain and potentially worse future in the later stages of dementia:

He was likely to die while he still knew us and while he was still at home, so once we'd got our heads round it we sort of, even though we were all frightened about what would happen, we accepted that it was probably a better outcome for my dad.

(09_daughter-caregiver)

I think if she hadn't had this breast cancer, although it was bad in the end, she'd have gone on for another two or three years and then you're dealing with somebody who is [...] who ends up in a home because you just can't cope.

(05_son-caregiver)

For some carers, the cancer diagnosis, in providing an 'end-point', helped uphold motivation and coping in their increasing caregiving role:

In some ways, because he had terminal cancer, you know there's going to be an end. Whereas if they've just got Alzheimer's and they're going to die of Alzheimer's, you don't know when that's gonna end. And because we knew he had a finite period of time, you can sort of pace yourself a bit.

(09_daughter-caregiver)

Care-recipients having an impaired understanding of their cancer was also highlighted as a positive by some participants. Several carers took comfort in the fact that they felt dementia had spared their relative of the anxiety associated with a cancer diagnosis, or of longer-term psychological impacts:

He doesn't even understand he had cancer, which is a blessing. I found that out 'cause when we were there I was talking to the doctor about something else and I mentioned his cancer treatment and he said 'I had cancer?!' (laughs). Amazing isn't it, that he doesn't remember. I'm glad because my God that man suffered, I'm glad in a way that if something has to be gone, I'm glad it's that.

(12_wife-caregiver)

4.2 Finding meaning through helping others

Although carers reported feelings of anxiety and low confidence in their caring abilities, many reported that they had acquired expertise over time, giving them "a real insight", including a unique understanding of the challenges of CDC:

It's made me have a wider understanding of social issues and health issues around having both dementia and cancer, which you can use positively.

(02_daughter-caregiver)

Participants expressed a desire to share their experiences and knowledge to help other carers of people with CDC:

The experiences I've had would be helpful to someone who's just starting down that road.

(02_daughter-caregiver)

I feel now I've come through the other side I want to help people, I feel like I can help people who are going through it.

(05_son-caregiver)

There was recognition that helping others was also beneficial for participants themselves. For bereaved carers, providing support to others seemed to afford them with a sense of purpose that had been lost with the caregiving role, and helped them to derive positive meaning from their experience:

I have now what could be an incredibly lonely life. I still miss my husband desperately, but if I had to lose him far too early in our lives...for me to be able to teach, to lecture, to share, to write, to help all these organisations, to help people to understand, then I think that's a pretty positive thing to come out of it.

(08_wife-caregiver)

Discussion

This is one of the first studies to focus exclusively on the experiences of family caregivers of people with CDC, and the first to provide an in-depth exploration of carers' psychosocial support needs and preferences. The findings substantiate and extend the few existing studies in this area to date, provide an in-depth understanding of the psychosocial challenges faced by carers of people with CDC, and can help inform supportive interventions and services for this caregiver group.

A need for CDC-specific information and resources

Our findings corroborate those of studies to date that emphasised the critical supportive role caregivers play in enabling people with dementia to access and manage cancer care and treatment (Courtier et al., 2016; McWilliams et al., 2020; Surr et al., 2020; Witham et al., 2018). This study found that carers of people with CDC struggled with the weight of responsibility of their relative's care, and this was exacerbated by a reported lack of targeted CDC-specific information and resources to help navigate their caregiving role. In particular, carers voiced a need for information regarding the symptoms and complications they

should be alert to and how to recognise these in a person with dementia, guidance for treatment decision-making (including the potential interactions of cancer treatment and dementia) and guidance for performing cancer-related medical/nursing tasks for a person with dementia (e.g. stoma care). AlzMed, an educational resource recently developed for supporting carers with managing medical problems for people with dementia, was found to significantly improve confidence in symptom-management and decrease role strain (Zimmerman et al., 2018). Development of a similar resource specific to CDC is likely to be beneficial for carers and could improve confidence in their caregiving role.

Moreover, the challenge of proxy decision-making in dementia has led to the development of promising decision aids, including those for carers of people with dementia (e.g. Einterz et al., 2014; Lord et al., 2016). Decision aids can help to increase knowledge about healthcare options and reduce decisional conflict (e.g. Cardona-Morrell et al., 2017; Ilic et al., 2015). Given that participants voiced decisional uncertainty and regret, and insufficient information to support informed treatment decision-making, carers of people with CDC may benefit from decision support specific to cancer care in the context of dementia.

Positive meaning-making as a coping mechanism for caregiving stress

This study is the first to highlight positive meaning-making as an important factor in coping for carers of people with CDC. 'Positive reappraisal' is a particular meaning-focused coping strategy whereby an individual attempts to redefine the meaning of a stressor by searching for positive aspects of the experience (Folkman, 1997). Meaning-focused coping strategies are particularly common and beneficial in low control situations, where stressors are not amenable to direct coping efforts (Biggs et al., 2017; Park & Folkman, 1997). Thus, owing to the chronic and/or progressive nature of cancer and dementia, where direct problem-focused coping strategies may not be particularly useful, it is not surprising that carers commonly used positive reappraisal strategies in an attempt to cope with their situation.

These findings suggest that encouraging and sharing positive perspectives and stories with caregivers of people with CDC may help them to reframe their own experience and improve coping. Ellis et al. (2017) found that the ability for caregivers of people with cancer and comorbid conditions to find positive meaning in their caregiving experiences was associated with higher caregiver quality of life. Further, interventions that facilitate positive reappraisals have been found to be effective at improving outcomes for older adults and caregivers of people with single conditions. For instance, a recent randomised controlled trial found that caregivers of people with dementia receiving a benefit-finding intervention focused on positive reappraisal reported significantly lower depressive symptoms and role overload after the intervention than those that received a standard psychoeducational intervention (Cheng et al., 2017). Future work could thus look to develop supportive interventions that facilitate positive reappraisal and meaning-making for carers of people with CDC.

A need for peer support for caregivers of people with CDC

Another key finding of this study that was evident across multiple themes, was the need for peer support opportunities for carers of people with CDC, in particular, for

acquiring CDC-specific knowledge and expertise and receiving emotional support from understanding others. Peer support is associated with lower levels of depression and anxiety, and greater confidence, coping and perceived social support in caregiving samples (Pillemer & Sutor, 1996; Shilling et al., 2013; Smith et al., 2018). People facing similar stressors are thought to be in a unique position of understanding to offer specific support that cannot be provided by those in the individual's existing support network (Helgeson & Gottlieb, 2000). Consistent with this, even carers who had good existing support networks or had sought dementia-specific peer support often voiced a need for peer support groups that were *specific* to their situation of CDC. Moreover, as peer support groups are based on fostering mutual aid, in addition to receiving support, participants also *provide* support to others through the sharing of their own experiences and knowledge (Watson, 2019). The Helper Therapy Principle argues that while helping others is beneficial for the recipients of support, individuals also derive benefit from providing support to others, such as an increased sense of competence or self-efficacy (Riessman, 1965; Skovholt, 1974). Indeed, carers in the present study, particularly those who were no longer in their caring role, felt they had acquired specialised knowledge and expertise over their caregiving trajectory and had a desire to help others in the same position as a way of finding positive meaning from their experience.

Reflective of the caregiver literature generally (e.g. Leinonen, 2011; Wolff et al., 2009), carers experienced barriers to attending in-person peer support groups. Online peer support interventions can offer greater accessibility and convenience (Sin et al., 2018; Wasilewski et al., 2017) and, similar to face-to-face support groups, have been found to have positive outcomes for participants (e.g. McKechnie et al., 2014; Mo & Coulson, 2013; Oh et al., 2014). Additionally, online support can reach and bring together larger and more geographically-dispersed groups of people. An online peer support community could thus facilitate bringing carers of people with CDC together, providing a sense of community with similar others that they do not otherwise have offline.

Implications for policy and practice

We have used the findings of this study to develop an online peer support forum specifically for carers of people with CDC, which is hosted by the UK's leading dementia charity (Alzheimer's Society UK, 2018). As well as peer information and support, the forum also hosts Question & Answer sessions with healthcare professionals with expertise in caring for people with a dual diagnosis of dementia and cancer, including a specialist Macmillan Dementia Nurse Consultant.

Health and social care professionals need to be aware of the additional emotional and physical burden experienced by carers of people with CDC, and the considerable constraints on their time, and proactively facilitate linkage to community support services and offer existing support resources for carers e.g. Macmillan and Dementia UK's information booklet for carers of people with CDC (Macmillan Cancer Support, 2020).

Our findings demonstrate the importance of dementia education and training programmes for oncology staff. One identified feature of effective dementia training programmes includes providing staff with a structured guideline to underpin their care practice (Surr et al., 2017). The development of more dementia-specific guidance

for cancer clinicians, like the recent UK guidance on caring for people with dementia during radiotherapy (The Society and College of Radiographers, 2020), could help support high-quality, person-centred cancer care for people with dementia and their families.

The findings also underline the importance of improving communication and co-ordination between healthcare professionals from different teams and specialities to achieve more integrated care for people with CDC. In particular, there is a need for greater involvement of dementia clinicians (e.g. geriatricians, liaison psychiatrists) in cancer-related treatment and care decision-making and planning for people with CDC.

Limitations

The sample size is modest, though appropriate for qualitative research underpinned by phenomenology (Robinson, 2014), and reflective of the challenges of recruiting carers, who have high demands on their time and energy. The sample included a wide range of ages (26–76 years), relationships to the care-recipient (spouse, adult child, grandchild, son-in-law), and cancer and dementia diagnoses, including seven different cancer disease groups. However, the sample were predominantly White British. While efforts were made to recruit a more diverse sample with regards to ethnicity and cultural background (i.e. the study flyer was shared with multiple minority ethnic organisations and community centres), these were not successful. This is not surprising however, given Alzheimer's Society report '3% of people with dementia are from black and minority ethnic (BAME) communities' (Alzheimer's Society UK, 2019), equating to around 25,000 people in the UK, and an even smaller number of these will have co-diagnosed cancer. Nevertheless, future work in this area needs to include more carers from minority ethnic groups, as dementia prevalence in minority ethnic communities will grow in the coming years (Alzheimer's Society UK, 2019), and previous research indicates cultural differences in family caregiving experiences and intervention outcomes (e.g. Lawrence et al., 2008; Katbamna et al., 2004; Belle et al., 2006).

The sample were also mostly women; largely female samples are common across carer research (e.g. Seal et al., 2015), and in general, family caregivers are predominantly women, in the UK at least (Office for National Statistics, 2017). However, men still provide a large amount of unpaid care, and research suggests differences in their experiences and a reduced likelihood of accessing support services in comparison to female carers (Milligan & Morbey, 2016; Morgan et al., 2016). Future exploration of differences in the support needs of this carer group with regards to sociodemographic and patient characteristics would provide insights for more individualised support for this carer group.

Lastly, this study was cross-sectional, though evidence suggests carers' needs change over the illness trajectory (e.g. Girgis et al., 2013; Halkett et al., 2018), and there is limited longitudinal research with carers of people with multimorbidity more generally (Price et al., 2020). Future longitudinal research could thus explore how carers' support needs may change over the cancer and dementia trajectories, and the longer-term impacts of their caregiving role.

Conclusions

Complex interactions of dementia and cancer present unique practical and emotional challenges for carers, who play a crucial role in supporting cancer-related decision-making and treatment for people with dementia. Carers expressed a strong desire for more cancer-related information and support, including peer advice and support, which is specifically tailored to navigating cancer care for people living with dementia and their families. One of our responses to this key finding has been to establish, in partnership with the UK's leading dementia charity, an online peer support forum especially for carers of people living with both dementia and cancer (Alzheimer's Society UK, 2018).

Data availability

The data for this study are available from the corresponding author, upon reasonable request. The data are not publicly available due to containing information that could compromise the privacy of research participants.

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