The key concerns of dementia family carers accessing a video-based online support service.

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Abstract

Aim

Around 60% of people with dementia live at home. The experience of caring for a family member with dementia can be rewarding and positive, but it can also be significantly stressful. Current healthcare policy is encouraging greater provision to support family carers, and online based interventions are gaining popularity with mental health service providers. This study provides an in-depth qualitative analysis of carer / counsellor sessions which took place online as part of an experimental video-based family carer-support intervention. The aim was to explore the key problems and difficulties self-reported by carers in the course of these sessions.

Setting

An experimental online video-based family carer support service.

Participants

26 family carers and 2 support service counsellors.

Design

Naturalistic video and audio recordings of support sessions between (n=101) taking place online over a 14-month period were transcribed and analysed thematically following the principles of grounded theory.

Results

Five main themes are reported on: *i) The role of the carer ii) Family tensions iii) Demands on the carer iv) Grief and loss v) Uncertainty and transition.* Key findings include: At the time of accessing the support service, many participants were in crisis; participants described the all-consuming nature of being a home dementia carer; they also reported social and psychological isolation; lack of appreciation by others for the caring role; tensions with other family members; uncertainty about the future; counsellors running the intervention reported widespread anticipatory grief and denial.

Conclusion

The findings of the study are in line with other research that has focused on the home dementia carer experience. It confirms that this particular care context generates an idiosyncratic range of difficulties that are not immediately obvious to outsiders and are rarely appreciated, even by those close to the carer.

Strengths and limitations of the study

- This was an in-depth qualitative study focusing on an exploration of the key problems and difficulties reported by family carers in the course of support counselling sessions.
- A representative sample of family carers using an experimental online support intervention took part in the study, with variations in age, gender and socio-demographic status.
- The principles of thematic analysis were applied to naturalistic recordings of online support sessions.
- The sample was drawn from a single region in the UK.
- Family carers using the support intervention were likely to be in crisis. This may have influenced what they reported.
- The study does not report on the longitudinal effects of the intervention.

Author contributions

JC designed the study and lead on the analysis and writing. PM designed the intervention and obtained funding. RYH & AB delivered the intervention, collected data and contributed to the analysis and writing. All authors commented on and approved the final version of the manuscript.

Background

Nearly two thirds of people with dementia in the UK live at home (Dept of Health, 2013). But while the experience of caring for a family member with dementia can be rewarding and positive, for the majority of carers it can also be significantly stressful (de Vugt & Verhey, 2013; Robertson *et* al, 2007). Family carers of people with dementia are often required to provide high levels of assistance, commit a large proportion of their time, and manage a variety of challenging behaviours in the people they care for. These can range from repetitive speech, wandering, and sleep disturbances, through to refusal of care, argumentation and violent outbursts (Gitlin *et al* 2010; Schulz & Martire, 2004). If unaddressed, these behaviours have been shown to accelerate disease progression, worsen functional decline and quality of life, and result in earlier nursing home placement (Gitlin *et al*, 2012).

For many family carers the perception that they are not properly equipped to deal with what may be a new and unexpected role can also be a considerable strain (Fauth et al, 2006; Ballard et al, 2000), and it can be a difficult transition from being a spouse, child or sibling to being a caregiver (Wenger, 1997). Social isolation for family carers can also be a problem because, although social attitudes towards dementia are changing, (Burgess *et al*, 2003) the condition is still widely associated with negative stereotypes such as the fear of losing one's independence and being a burden to others (O'Connor & McFadden, 2010). As the family member with dementia becomes progressively more dependent and the demands placed upon the caregiver's time and emotional resources become more consuming, family tensions arise (Kramer *et al*, 2006), not least because of the damaging and unpredictable effects that dementia can have on communication and cognitive processes – even in its early phases.

In the light of ongoing dementia-focused policy initiatives (Dept. of Health, 2009; 2015; 2016) support for family carers is becoming more of a priority. Although admittedly patchy, there has been an increase in funding for well-established services such as respite and day-care, and extra provision for informal support groups and networks. There has also been considerable interest in developing support services that use talk-based therapeutic approaches and communication-focused training for carers of people living with dementia (McKechnie et al, 2014). The objective often being to provide longitudinal dementia-specific support for carers rather than one-off crisis intervention or generic listening services. However, although, many such interventions are successful in terms of improving carers' knowledge of communication skills and strategies, only a minority actually have an impact on their levels of wellbeing. Morris *et al* (2017). It has been suggested that one reason for this is that many interventions lack, or fail to adequately integrate, an appropriate theoretical model (Morris *et* al, 2018), and that this shortcoming can prevent an understanding of the mechanisms through which beneficial effects are realised (Elvish *et al,* 2013).

The analysis presented here is based on a corpus of naturalistic audio and video recordings made of sessions between specialist counsellors and family carers who were using of an experimental online communication-based carer-support intervention *Empowered Carers,* which is currently being piloted across several NHS trusts in Greater Manchester. This study comprises part of a mixed-method evaluation which sought to measure the effectiveness of the intervention and explore the micro-interactional features of carer-counsellor interaction in a video-conferencing based setting (Chatwin and Mcevoy, 2019). Here, we focus solely on an in-depth qualitative analysis of sessions which took place between specialist counsellors and family carers using the intervention. The primary aim being to explore the self-reported problems and difficulties that were described by carers in the course of their interactions with a counsellor.

Empowered Carers is a communication-based support intervention based on the well-established New York University Caregiver Intervention (NYUCI) (Gaugler *et al*, 2011; Mittelman, *et al,* 2004). This approach has been widely adapted in settings around the world since it was first introduced in the late 1980s (Fauth et al, 2019). It generally consists of an initial course of 4 or more sessions of individual or family counselling, followed by additional on-demand telephone support. The programme may also include access to a support group or informal support network. In the case of *Empowered Carers*, the intervention consist of an initial face-to-face session with a main carer and regular follow-up sessions offered via a secure online video-conferencing ap. Specialist dementia-communication trained counsellors work with carers to build up their emotional resources so that they can better deal with stress caused by the challenging situations they encounter. Counsellors are also able to offer practical advice and guidance on dementia. The frequency of follow-up sessions is negotiable depending on the needs of the carer. As with the NYUCI, where appropriate the intervention may also incorporate elements of family counselling involving members of the carer’s wider family group. These multi-party sessions are also conducted online using the video-conferencing platform. A more detailed outline of the development of the intervention is reported elsewhere (Chatwin et al, 2020).

Methods

Sample

26 family carers and 2 counsellors took part in the study. The dataset was comprised of 70 support session recordings (18 audio and 52 video). The average length of a sessions was approximately 50 minutes; the longest 95 minutes, and the shortest 16 minutes. The entire data set represented approximately 48 hours of recorded material. 14 participants were looking after a spouse, and 6 were caring for their mother. 1 cared for his father, and 1 for their sister-in-law. 12 participants were still employed and 13 were retired. 2 self-identified as a ‘full time carer’. (See Table 1, below.)

Table 1. Makeup of the sample

Participant No	D.O.B	Occupation	Cares for:	D.O.B	With: (type of dementia)	Online / phone	Sessions
1	9.6.1941	Social worker (Retired)	Wife	21.2.1948	Mixed	Online	3
2	not given	Civil servant (Retired)	Wife	not given	Lewy Bodies	Online	14
3	not given	Secretary (Retired)	Wife	2.6.1935	Vascual	Phone	10
4	not given	Social worker	Mother	not given	Alzheimers	Online	7
5	13.5.1970	Administrator	Mother	18.7.1946	Vascual	Online	7
6	8.11.1956	Salvation Army Minister	Wife	not given	Alz & Vas	Online	16

7	not given	Shop worker (Retired)	Husband	not given	Vascual	Phone	20
8	not given	Secretary (Retired)	Husband	not given	Vasual/Parkinson	Phone	13
9	29.8.1972	FT carer	Son	not given	Alzheimers	Online	15
10	not given	FT carer	Mother	not given	Alzheimers	Online	15
11	not given	Banker (Retired)	Mother	not given	Vascular	Phone	9
12	11.12.1947	Housewife (Retired)	Husband	17..06.1946	Lewy Body	Online	17
13	not given	Teacher	Wife	not given	Alzheimers	Online	6
14	17.09.1967	Dancing teacher	Mother	not given	Alzheimers	Online	7
15	13.07.1965	Architect (Retired)	Mother	not given	Alzheimers	Online	14
16	31.08.1944	Engineer	Husband	not given	Alzheimers	Online	10
17	01.01.1944	Housewife (Retired)	Husband	not given	Parkinsons	OL/ phone	7
18	23.7.1989	Maternity support work (Retired)	Daughter	05.01.1956	YOD	Online	7
19	not given	Finance worker	Daughter	16.4.1953	Alzheimers	Online	6
20	02.04.1944	Banker (Retired)	Sister in Law	not given	Vasc/Alz	Online	6
21	14.05.1941	Cleaner (Retired)	Wife	16.09.1938	Vascual/Alz	Phone	6
22	not given	IT Technician	Husband	not given	FTD	Online	3
23	22.03.1965	Factory work	Daughter	02.02.1939	Vascular	Phone	3
24	not given	School admin	Daughter	not given	Alzheimers	Online	3
25	09.05.1948	Teacher	Wife	05.04.1944	Alzheimers	Phone	2
26	not given	Factory worker (Retired)	Husband	07.08.1953	Alzheimers	Online	2

Recruitment

Anybody in the Greater Manchester area who was caring for a person with dementia at home was eligible to use the *Empowered Carers* support service. Referrals were made via the local NHS and non-NHS dementia support services that participants were already engaging with. For example, Age UK, Greater Manchester Mental Health NHS Foundation Trust, and local dementia day care and respite providers all made referrals. A small number of carers self-referred after seeing publicity about the initiative. Carers who followed up a referral were offered an introductory face-to-face to face or telephone session with an assigned counsellor. At this point they were also offered the choice of whether or not to take part in the study and have their sessions recorded. Participants who gave preliminary consent then had the period between this initial contact and their first session (1 to 2 two weeks) to confirm participation. There were 56 referrals to the service during the data collection period, and of these, 26 agreed to participate in the study.

Analysis

Analysis followed the principles of grounded theory (Glasser & Strauss, 1967). Verbatim transcriptions of the entire corpus of recordings were initially produced by a computerised auto-transcription service (Otter.ai). Nvivo 12 qualitative analysis software was then used to compile and organise the data set. The auto-transcribed data were analysed using a process of focused coding, categorisation and thematic development. Session transcripts incorporated a time code so that the entire corpus could be accurately cross-referenced with the original recordings. As more refined thematic collections were developed, relevant shorter sections of transcription data were re-transcribed manually by the researcher to ensure accuracy. Emergent themes were discussed within the project team and with the participating counsellors in an ongoing process. This enabled potential early findings to inform subsequent thematic searches. Meanings drawn from the counsellor's personal session notes, discussions with the wider team involved in delivering the intervention and interpretations arising during the research process were also incorporated where relevant.

Results

Five main themes emerged which encompassed key elements of the home dementia care experience as described by participants engaging with the service. The themes were: *i) Isolation ii) Family tensions iii) Demands on the carer iv) Grief and loss v) Uncertainty and transition.* These were largely, but not exclusively, reported during the early phases of support sessions, when counsellors were likely to be initiating discussions about the issue or issues which were causing most concern to the carer (Chatwin et al, 2014). These phases of the counselling or other talk-based therapeutic encounter are roughly analogous to the 'presenting complaint' phase in routine medical consultations (Chatwin, 2013; 2006). However, in a counselling support setting such as this, the root of an issue may not be immediately apparent – particularly if a person is in crisis. This meant that some participants were only ready to discuss their key concerns far later in the therapeutic process.

i) Isolation

Participants frequently commented on how isolating the home caregiving experience could be, and how difficult it was for people who were not directly experiencing it to understand this. Participants also highlighted the way in which the profound emotional and practical changes that they were experiencing were often not appreciated by those around them.

> I think it's sometimes it's very easy for people to judge and just to see you for like, half an hour, you know, or an hour or a couple of hours. You're living each other 24 seven, and you are the best judge of what it is like.
>
> *Participant 8*

> The biggest thing is not going out. I haven't been food shopping even for three weeks, so I've not even been to the supermarket. So it's like you feel tied in. I just feel very isolated at times.
>
> *Participant 19*

> Yeah, it's a spiral - up and down - like you're on your own, because there's no one else that you talk to about it. And you feel like you're the only person [who] does this thing.

Participant 10

> It’s just the non-stop nature of the condition, you know, there's no end. No signing off from it like you do in a nine to five job. [At the moment] it's through the day and it can be through the night as well. The 24 seven is relentless.
>
> *Participant 14*

> It's difficult because you don't know where to turn. You don't know who to look to for help, or where to go. You're on your own basically, you're trying to do the best and you're always doubting yourself because you think am I doing the right thing?
>
> *Participant 5*

> The [level of stress] varies because if she's stable [PWD] like she is now then it doesn't really affect my daily life. But I feel like I'm on edge all the time because I'm just waiting, and the longer she's stable, the more anxious I get. Because I think well, it's been three weeks now something's gonna happen soon.
>
> *Participant 18*

ii) Family tensions

For some participants, taking on a full-time caring role generated tensions with other family members. If family lived locally, for example, these might relate to disagreements over the amount of support that they were prepared, or able to offer. It was also sometimes the case that where more than one son or daughter was in a position to take on care of a parent, the task had fallen to a just one of them. Carers reported feeling isolated from, and even resentful of, other family members who did not have to deal with the everyday reality of full-time dementia care.

> It's not his fault [PWD]. It's just the situation. And actually, it's not him, it's my mom. But I suppose him having dementia has made situation much more difficult for all the family members. Well, I mean, it's difficult, isn't it when you're dealing with a mother, who's an alcoholic. Whether my dad's got dementia or not, she's gonna be a nightmare. She's just more of a nightmare because of him because I think it’s negatively impacted on her. It's certainly not brought us closer together. It’s had a positive impact on me and my brother's relationship, but a negative impact on hers because she's just not doing well with it at all.
>
> *Participant 24*

> [Carer is discussing his decision to stop having home help.] It was my sister pressuring me to do it. I would have never done it myself. It was because I was getting pressure from family members and that. My mom will stay at my sister’s and she’ll start moaning about me. But they take her too seriously, because they don’t know when she’s with me she’ll moan about them too. They don’t recognise the problem like that you know. I think they do now a bit – they’ve done nothing since I’ve stopped the carers.
>
> Counsellor: Would any of your family be interested in joining our sessions do you think?

> Carer: No! [laughs] I can't put it any straighter than that to you, you know what I mean? My brother might, but I doubt the rest of them would at all. They're too busy with their own lives. They like telling me what to do when they come here, but I don't think they'd like to admit to other people how they are.
>
> *Participant 9*

iii) Demands on the carer

For many carers the practical difficulties of looking after a person with dementia were intensified by the relentless nature of the role.

> Mostly through the nights he's just hallucinating, talking, tossing and turning and confused, and there's a likelihood that he's going to give me a slap unintentionally. So I'm sort of perched on the edge of the bed not being able to relax. It makes it really difficult for me to sleep. For most of the last three weeks I've been going to sleep in the lounge on the settee, when it gets too much. A few times I got to the point where I was just crying because I was so sleep deprived. How long I can carry on going I don't know.
>
> *Participant 6*

> You know, I have to do everything now. Absolutely everything. Like sorting bills out, sorting the money out, and I do - I've always done it. But now I find I try to put it to one side, but I've got to do it and so I do get stressed, all stressed out. I try and think I'll do it later and you shouldn't, you should do it there and then and get rid of it shouldn't you really. Yeah I do get stressed up you know, I think oh, God, I've got to do this, or I've got to do that.
>
> *Participant 3*

> With the way things have been going, I can't do anything. I can't do the housework, I can't do any shopping. He's just constantly stumbling about, even when my sisters are all here on Sunday. Also now when he's eating, it's everywhere. It's all over his face and down his clothes. So then I'm having to use baby wipes to wipe his hands and things like that. And obviously because he's always been very well groomed, he's sees all this food all over him, wonders why I have dressed him in these [old] clothes and gets distressed because he's forgotten that he was eating.
>
> *Participant 6*

> It's not just her [PWD]. I think it's not her at all really. It's about the fact that she's in this situation and she would hate it if she knew what was going on. So I mean, it's partly the fact that she doesn't know what's going on that's the problem. It's like she'll says things like, 'I don't know why I can't think clearly'. And so she's got that, but that's the bit I don't like. I'd prefer it and if she was totally unaware of it, but she's not and that's why I don't like. It's that constant knowing that she doesn't feel calm.
>
> *Participant 21*

> I think still very sadly there is still a stigma, negative stigma around people living with dementia and sometimes people just latch on to that and it's not always reality.
>
> *Participant 8*

iv) Grief and loss

Many participants reported experiencing grief at the loss of the person as they knew them, or if they did not choose to label their feelings as such, often described a complex mixture of other emotions. These might include fear and worry about their future once the person they are caring for has gone (either died or finally been admitted to a care home). Guilt over having accepted the situation, or a feeling that one is giving up hope were also reported.

> Obviously with me it was my mom - someone who I'd go to and share problems with. And so yes, it's a lot of sadness and grief really. And because my mom has dementia, I'm sorry I'm losing her. I've lost the person that she was. Life as a carer is a lot of different emotions. [For me] the overwhelming one is a sort of sadness and confusion but it's a lot of different ones rolled into one really. It's very frustrating.
>
> *Participant 5*

> I think it's the nature of the beast really isn't it - this particular situation. I hear other people say as well, it's a situation where it's like you're mourning but you're mourning while the person's living. It's like they're a dead vessel. Part them is dead to you, they're not the same person but they're still there.
>
> *Participant 15*

> It was like I think I was resisting it [arranging a care home]. So even though I was doing all the things I was meant to be doing, and going to look at homes, picking them and making sure it was right for her. It was like there was a guilt thing as well. You feel guilty for putting somebody in a home. Because I think because she's so young. You know, you hear people say no, oh, don't ever put me in a home. Well we never had that conversation with my mom because she was diagnosed very early and she declined very quickly. So we've never had that. I didn't know what her wishes are, and you see people who look after their family members [at home] but I just couldn't physically have done that. So that makes you feel a little bit guilty.
>
> *Participant 18*

v) Uncertainty and transition

Caring for someone with dementia at home is an uncertain process. There is the ever-present knowledge that the situation will inevitably become more and more difficult as the person with dementia declines. However, because of the highly individualised nature of dementia this is made considerably more stressful by worries about what these difficulties will actually involve. A sense of having lost control, or of having little certainty over the future course of events was a reoccurring theme among participants.

> Somebody from the memory clinic came in at the end of March to check on his medication.
> And he [PWD] said. 'I want you to write down all the things I've got to ask.'
> I said. 'Well, what have you got to ask them?'
> 'Well, what's going to happen to me?'
> I said. 'I'll tell you exactly what she'll say. "Everybody's different. We can't tell you." cuz I've asked and people laugh.' And that's the answer everybody gives you.

Participant 12

> At the moment, that's my biggest worry, that I didn't do enough if she suddenly passed away. Could I have done something more? And at times that could be from a very selfish perspective, could I have done more to extend [her life] to a time where I was better to cope, rather than just prolonging her life unnecessarily. And that's a selfish thing for me to say, but that's at the back of my mind. If I could just push it to a point where I could cope with it.
>
> *Participant 13*

> I went into the daycentre last Thursday and they just happened to ask how everything was, and I just got overwhelmed. The night before I'd actually been thinking whether to walk out the house and just carry on walking and escape, which was scary because the alternative was to get a pillow and just cover [his] face with it. It's not quality of life for him. It's not quality of life for me.
>
> *Participant 6*

By its nature, the period spent caring for a person with dementia at home is likely to be transitional. How long this transition will be, and how it will end (either when the PWD dies or goes into full-time residential care) is an open question. This uncertainty was another source of stress for many carers.

> We just don't know what's going to happen. I mean, if I knew that she was going to die in a year's time. You know, next year, my mom will be dead it'd be awful because you'd be ticking down the time. But in a way, it'd be a release. But it's just like it's going to go on and on and on.
>
> *Participant 15*

This kind of emotional stress was not always resolved, even when the person being cared for was admitted into residential care and is technically no longer their responsibility. For participants who reported going through this process, the transition to a care home brought its own set of emotional stresses. Although on the one hand, no longer having one's life subsumed by the caring role might signal a degree of release or freedom, on the other hand, an entirely new set of concerns might be triggered.

> I wish, I wish I could let go really. I'm a bit like my mom [PWD] in that respects. It's I think it might even be a control thing. Okay. Not control of her but control of my life. Knowing that she's okay. So in some ways, it's kind of like you go in every day you almost need to go every day to feel in control.
>
> *Participant 4*

Discussion

Over the course of their sessions participants described in great detail the challenges they faced while caring for a person with dementia at home. It is well established that although the experience of looking after a family member with dementia can be rewarding and positive, for the majority of carers it can also be significantly stressful (de Vugt & Verhey, 2013; Robertson *et* al, 2007). This was supported by our findings. However, it should be remembered that all of the people who took part in the study were voluntarily accessing a carer support service, and so would by definition be at a point where they felt that they were not coping as well as they could. This was confirmed by the two support counsellors who ran the service. Both reported that the majority of cares they engaged with could be considered to be in crisis, with many in a state of denial when they first made contact.

Participants described the all-consuming nature of being a home dementia carer – how difficult it seemed to be for other people to appreciate the effect that the caring role was having on them and how stressful and frustrating it could be. Many other studies have highlighted this point (de Vugt et al, 2013, 2006) and it has been the focus of numerous psychosocial interventions (Liu et al, 2018; Brooks et al, 2017). So too with isolation (Banburry et al, 2019). Different types of isolation were evident in our carer accounts. On one level there was the purely physical isolation that could result from the practical demands of the role: carers reported being unable to leave the person they were caring for alone for any length of time, and this could severely limit their ability to go out or have routine social contact. But there were also incidental effects caused by the withdrawal or distancing of friends and acquaintances. This kind of distancing is often reported by carers of people with dementia (Beattie et al, 2004) and other serious illnesses (Green, 2009). Significantly, the fear of stigma or embarrassment over the behaviour in public of the person with dementia (Roach et al, 2008) did not appear to be a significant factor here.

At another level, carers reported feeling isolated from, and even resentful of other family members who did not have to deal with the everyday reality of full-time dementia care. The relationship between the family dynamics of caregivers and the likelihood of caregiver depression is well-established (Torossian & Ruffins, 1999). Sutter et al (2014), for example, found that families with better communication styles, empathy, and flexibility are more effective in managing the conflict emanating from caregiving roles and duties. This was evident in the accounts we collected. Although the term family carer ostensibly implies a degree of external group support, some participants found that seeking (or expecting) help from their family caused tension. In cases where family support was reported it could range from simply 'being there' to listen and share the emotional burden, right through to practical and financial support. This might include the equal division of care duties and facilitating respite care. Where serious problems and tensions arose, these usually related to disagreements over the amount of help – in whatever form – other family members were prepared, or able, to offer. It was also the case that not all support was welcome. Some carers found the involvement of other family members an intrusion. Particularly if they regarded their family as having little understanding of the everyday reality of their situation. There were also situations where, if there were multiple siblings, the carer role fell to just one of them. This could cause ill feeling and resentment, but as with many of the family related issues that emerged, these often had their roots in pre-existing tensions. Not all carer / family dynamics were troublesome. There were accounts of families – or particular relationships within families - becoming closer as a result of caring for a person with dementia, although this was unusual. A further complication for one carer was the fact that they actively disliked the person they needed to care for and fulfilled their caring role out of a sense of duty, bothered by an underlying sense of guilt.

For many participants, the practical difficulties of caring for a person with dementia were intensified by the relentless and unpredictable nature of the role. The stress caused by the need to remain attuned for any potential crisis led to an inability to 'switch off' – or even to sleep properly – for many. A number of carer-burden studies have shown sleep disturbance to be highly prevalent in both people with dementia and their carers, and to impact significantly on their quality of life (Lee & Thomas, 2011; Arber & Venn, 2011; Bruce & Patterson, 2000), and sleep deprivation caused by the disturbed sleep patterns of the person with dementia itself was another significant stress vector for participants.

Caring for someone with dementia at home is an uncertain process, and by its nature is going to be a period of transition. How long this transition will be and how it will end (for example, when the PWD dies or goes into full-time residential care) is an open question. Added to this there is the ever-present knowledge that the situation will inevitably become more and more difficult as the person with dementia declines. However, because of the highly individualised nature of the condition this is made considerably more stressful by worries about what these difficulties will actually involve. Along with purely practical concerns such as whether or not they will be able to cope physically with the care burden, participants often described a complex mixture of emotions which accompanied the gradual loss of the person they cared for - loss of meaningful communication, emotional closeness, and aspects of personality (Caitlin, 2010). Such losses are known to prompt the experience of grief prior to death in some individuals (Meuser & Marwit, 2001; Marwit & Meuser, 2002; Adams & Sanders, 2004) Although it was only occasionally referred to directly by participants, both counsellors working on the intervention regarded many carers to be strongly indicating anticipatory grief. Holley & Mast, (2010) point out that this kind of grief response can also arise as a result of loss of personal freedom, worry about the future, changes in roles and role conflict, and disruptions in functioning. All of these elements were present to some degree in the narratives of our participants.

Currently, although medical and lay awareness about dementia issues in general is on the ascendant (Cronin-Davis et al, 2009) the idiosyncratic collection of psychosocial issues that it engenders remain at the margins of public awareness (Page & Keady, 2010). This makes it all the more difficult for family carers of people with dementia because, as the findings from this study confirm, they face a range of specific problems that do not necessarily impact on those home caring for people with other terminal illness, such as cancer or heart failure. Carers in our study reported anxiety over trying to follow the wishes of the person they cared for once they had lost capacity. Unlike other conditions that can involve an extended period of home care before a person passes away, or transitions into nursing or hospice care, the loss of cognitive abilities that accompany dementia can mean that carers find themselves in a position where the wishes of the person they care for have not been clarified before the illness removes capacity. Selman et al (2007) devote a significant part of their study on home carers of terminally ill heart failure patients to the discussions that take place around end of life care preferences. Similarly, there is an established body of literature advising on how health-care professionals can approach these interactions (Mori et al, 2013; Keating et al, 2010). In the case of dementia home carers however, the key reference points needed to underpin these discussion: such as prognosis, potential future symptoms and end of life preferences (Clayton et al, 2007; Clayton et al, 2007) are often not clear at the point in the illness trajectory when a person has capacity to engage with them. Furthermore, during these earlier stages such discussions may not seem appropriate, and reports of them having taken place were significantly absent from our data. This was in contrast to numerous accounts of carers struggling to 'do the best thing' for their relative without really knowing what their wishes might have been.

The emotional and psychological stress felt by the carer is not always resolved, even when the person they care for is admitted into residential care and is technically no longer their responsibility. For participants who reported going through this process, the transition to a care home brought its own set of emotional stresses. Although on one hand, they were no longer totally subsumed by the caring role, on the other hand, they now experienced fear and worry about the future care that their relative might experience and occasionally, feelings of guilt over having somehow failed the person they cared for.

Conclusions

This study examined carer accounts that were embedded within ongoing therapeutic encounters. The themes and issues that emerged were the result of concerns that family carers raised themselves – often while they were actually in crisis – rather than as the result of later self-reflection, such as in an interview setting. We would suggest that this gives them a depth and contextual underpinning that would have been difficult to achieve using comparable qualitative methods. The findings of the study are largely in line with other research that has focused on the home dementia carer experience. It confirms that this particular care context generates an idiosyncratic range of difficulties that are not immediately obvious to outsiders and are rarely appreciated, even by those close to them.

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Competing interests

None declared

Participant consent

Obtained

Ethics approval

Approval for the study was obtained from the University of Salford Research Ethics Committee. Approval No. HSR1819-020. 09-02-2019.

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