**Abstract**

**Objectives**

This study aimed to explore carers’ experiences of supporting a family member or friend with dementia through COVID-19 and experiences of hope and resilience during this time.

**Methods**

Qualitative longitudinal research was undertaken in the UK, with thirteen unpaid carers of people living with dementia who took part in two semi-structured interviews 8 weeks apart between June and October 2020. All transcripts were analysed using reflexive thematic analysis.

**Findings**

Four themes were developed and included: COVID-19 impacted negatively upon everyday living; carer resilience: adapting to COVID-19; analysis of risk: safeguarding the person living with dementia; and thinking about the future with COVID-19.

**Conclusions**

The results illustrated how the sudden changes which occurred during the pandemic negatively impacted on carers and people living with dementia in several ways, including additional responsibilities and taking away hope. The importance of continued formal and informal support for carers and people living with dementia during COVID-19 were highlighted. Formal services, care homes, and organisations need to be supported to implement procedures to ensure a safe environment during future lockdowns or periods of social restrictions. This will enable carers to remain visiting their family members and increase their confidence in accessing services and allowing paid carers to support their family member with dementia. These results have also illustrated the resilience of carers, who adapted to sudden changes which impacted negatively on their wellbeing and the wellbeing of the person living with dementia.

In the UK, it is estimated that over 670,000 unpaid carers provide support for a person living with dementia (Carers Trust, 2015). In this article, the term ‘carers’ is used to describe unpaid informal caregivers who support a family member or friend living with dementia; this may be as co-habitants or in the residence of the person living with dementia. Carers report both positive and negative experiences of their caring role which can impact upon their quality of life (Peacock et al., 2010; Shim et al., 2013). For example, some carers describe gaining a sense of achievement and meaningfulness through providing care (Sanders, 2005). However, prolonged care provision can lead to negative outcomes such as increased burden, uncertainty, isolation, and instability (Cassie & Sanders, 2008).

In March 2020, the UK Government introduced restrictions to reduce the spread of COVID-19. The type and severity of restrictions varied over time, and included both national and local lockdowns, social distancing, and mask wearing. Throughout this period the social assets (e.g., family, friends, peer support groups, General Practitioners (GPs), social services, and respite care) carers relied upon to ensure their own wellbeing, and the wellbeing of the person living with dementia, were severely disrupted (Giebel et al., 2020a; Sriram et al., 2021). This negatively impacted upon the wellbeing of many carers (Sriram et al., 2021).

Recent research by Dementia UK (2020) found that during COVID-19 restrictions carers experienced an increased feeling of loneliness and isolation, and an inability to access the care and support services they or the person living with dementia needed. 86% of the 169 respondents stated that their wellbeing reduced during COVID-19, and 78% stated that the wellbeing of the person living with dementia had also reduced. Other research highlighted that carer may have taken on additional caregiving duties during the pandemic, sometimes to avoid the risk of others spreading COVID-19 to the person living with dementia (Wang et al., 2021; Sriram e al., 2021). For carers of a person living with dementia residing in care homes, it is unlikely that they took on additional caring responsibilities as care home procedures limited access to their loved ones, however this may have had negative implications for the carers’ wellbeing due to increased worry and an inability to ensure proper care.

Carers’ quality of life is influenced by a multitude of interrelated factors, such as the availability of, and access to, social and professional support, their physical and mental health, and their relationship with the person with dementia (Farina et al., 2017). Research has also illustrated the importance of resilience, with carers with high resilience reporting lower levels of depression (Altieri & Santangelo, 2021). Windle (2011, p.163) defined resilience as “the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation or “bouncing back” in the face of adversity”. Resilience is one element of carers’ experiences we aimed to explore in our research. In our article, resilience is not considered as a psychological trait but is viewed through an ecological resilience framework which asserts that carers call upon individual assets (e.g., psychological, biological, and material resources), as well as community (e.g., family relations, social support, and social participation) and societal (e.g., employment, health and social care, social policies) resources, which interact to mediate or impede resilience (Windle & Bennet, 2011).

Few studies have examined resilience within carers of people living with dementia during COVID-19. Altieri and Santangelo (2021) identified that whilst carers with high resilience reported lower levels of depression and anxiety before lockdown compared to carers with low resilience, carers with high resilience reported significant increases in anxiety during lockdown, whereas carers with low resilience displayed no significant increase in anxiety. This suggests that resilience may not moderate carer’s wellbeing during atypical events such as a global pandemic. This research however was quantitative in nature and therefore unable to provide understanding of carers’ experiences of resilience during this time. Hanna et al. (2021) provided insight into how family carers maintained their resilience during COVID-19. The researchers identified the importance of clear communication from organisations and support/health services during the pandemic, and between family carers, which reassured carers when making decisions, and enabled carers to share the burden. Other protective factors included use of personal protective equipment (PPE) to protect the person living with dementia, supportive social networks which allowed carers to lessen the additional burden of care, and coping mechanisms (e.g., exercise and access to green spaces) which had a positive impact on carers’ wellbeing. However, as data were only gathered at one timepoint, researchers did not capture experiences across time within the rapidly changing environment created by COVID-19.

Hope can also be an important psychosocial resource in the mental and physical health of carers of people living with dementia (Duggleby et al., 2009; Irvin & Acton, 1997) but one which is “largely neglected” (Duggleby et al., 2013, p. 1). Hope is a “dynamic experience of possibilities for a better future” (Duggleby & Williams, 2010, p.1). A small body of literature has illustrated that hope can support psychological, spiritual, and physical health of carers of people living with dementia (Duggleby et al., 2009). For example, Irvin and Acton (1997) highlighted that hope mediated the relationship between stress and well-being in women caring for family members with Alzheimer’s disease. The important role of hope was further supported by Duggleby et al. (2011), who used a mixed methods design to study hope and its impact on the quality of life of family caregivers of people living with Alzheimer’s disease. They found that hope was significantly related the subjects’ perceptions of their overall quality of life as well as several other domains of quality of life, including physical, psychological, social relations and environmental domains. Therefore, alongside resilience, hope can be an important psychosocial factor that can influence the quality of life of carers of people living with dementia. However, as carer’s access to much of their social and professional support was limited during COVID-19, this is likely to have impacted carer’s hope for the future. To the authors’ knowledge, no research has explored carer’s experiences of hope during the COVID-19 pandemic.

Currently, few qualitative studies have explored the experiences of carers during COVID-19 and no study has explored these experiences using qualitative longitudinal research. Existing research has highlighted a snapshot of the potential negative impact of COVID-19 (e.g., increased feelings of loneliness and isolation, an inability to access the care and support services, and taking on additional caregiving duties; Harris & Titler, 2021; Tuijt, et al., 2021), but this has been at one time point and has not captured how these experiences changed through COVID-19 for their participants. There is still a need to further examine carer experiences and how these changed across time during the pandemic. Therefore, using qualitative longitudinal research, with participants taking part in two semi-structured interviews 8 weeks apart, this study aimed to explore carers’ experiences of supporting a family member or friend with dementia through COVID-19 and investigate experiences of hope and resilience during this time.

**Method**

**Methodology**

The COREQ Checklist has been used to report this qualitative study (Tong et al., 2007). This study utilised a qualitative longitudinal research (QLR) methodology (SmithBattle et al., 2018; Tuthill et al., 2020) with carers being interviewed at two time points approximately eight-weeks apart. Within QLR, it is not only the chronological passing of time that creates meaning, but also how the individual experiences that passage of time (Saldaña, 2003; Tuthill et al., 2020). An eight-week gap allowed for in-depth exploration of the rapid changes in COVID-19 guidance and restrictions at the time of data collection (June 2020). Therefore, QLR provided a unique understanding of carers experiences across time by generating comprehensive data that would have been less evident through cross-sectional or quantitative data alone (Tuthill et al., 2020). QLR centres on human experience being both a construct of participant’s personal reflections and researcher’s understanding of them, consequently noting the simultaneous existence of multiple realities (Balmer & Richards, 2017; McCoy, 2017). Thus, this research was underpinned by a critical realist ontological position, acknowledging the existence of a real physical reality which people have their own understandings and views of (Fletcher, 2017). Also, a contextualist epistemological position, acknowledging that a person’s capacities to objectively ‘know’ such realities are tied to their sociocultural context (Pynn, 2016).

**Participants**

All participants were recruited from across the UK between 15th June and 12th August 2020 (please see House of Commons Library (2021) for a timeline of COVID-19 guidelines and restriction in place during participant interviews). The inclusion criteria stated that participants had to be 18 years old or over, live in the UK, and currently be an unpaid carer of someone with dementia. Those who did not speak English or were unable to provide informed consent were excluded.

A total of 13 carers, consisting of 10 female and three male participants, with an age range of 31-75 years old (mean=58 years), were recruited through purposive sampling. Participants were recruited across the UK through local carer organisations, dementia carer groups’ social media, and Join Dementia Research. A poster providing details of the study and a Qualtrics link to the information sheet and consent form was shared across the platforms. Potential participants clicked on the Qualtrics link to access the information sheet and to provide consent, demographic details, and contact details.

**INSERT TABLE 1**

**Data collection**

Data were collected through 26 recorded, semi-structured interviews by either DH (male) and JR (female), who are both psychologists and experienced qualitative researchers. Participants took part in two interviews each (approximately eight weeks apart), to capture any COVID-19 related changes. None of the authors were known to the participants prior to their interviews. All interviews took place remotely over Microsoft Teams, Zoom, Skype, or by telephone. Interviews were guided by a topic guide (please see supplementary documents for both topic guides) which was informed by the research aims and developed through a collaborative process between DH and JR. The interview one topic guide asked questions that explored how carers experienced their caring role from the start of Covid-19; how the day-to-day lives of carers were impacted upon from the start of Covid-19; what helped unpaid carers to maintain their wellbeing; and what were carers' experiences of hope and resilience through Covid-19. The interview two topic guide asked similar questions, but these explored any change from the participant’s first interview. The interview two topic guide was adapted to the changes between the participant’s first and second interview, and where appropriate, to the preliminary analysis. Interviews were transcribed verbatim and anonymised by the authors. No participants took the opportunity to look over and amend their own transcript.

**Ethics**

Ethical approval was provided by Staffordshire University Ethics Committee (SU19-137-RN). All participants were made aware that participation was voluntary and provided written and verbal informed consent prior to participating in an interview. Participant names have been replaced with pseudonyms.

**Analysis**

Transcripts were analysed on NVivo using an inductive, semantic, (critical) realist approach to reflexive thematic analysis (RTA; Braun & Clarke, 2019). Analysis began once all the data were collected. Data were analysed through the different stages of RTA, starting with each author familiarising themselves with the data by reading each transcript and making initial notes of anything of interest. The transcripts were divided between three of the authors (DH, JR, and ID) and each author coded their participant data. Codes were then discussed across the team to help refine the coding process and ensure a more systematic approach. Codes and data were discussed as a team to develop initial themes which captured broader patterns of meaning across the data. Once satisfied with the initial themes, the authors started to further review and refine these to ensure they were underpinned by a central concept, captured the data, told a convincing story, and addressed the research aim. Any disagreements across the stages of the analysis were discussed within the team during analysis meetings, with the outcome agreed upon by consensus. As a key element of this methodology was the use of QLR, both interviews for each participant were analysed together to better enable exploration of change across the two interviews and these were highlighted within our thematic analysis document.

**Findings**

Four main themes were developed during analysis, these, and their subthemes, are presented in table 2.

**INSERT TABLE 2**

**Theme 1: COVID-19 impacted negatively upon everyday living**

This theme captures how the sudden changes experienced during COVID-19 restrictions impacted negatively on the lives of carers and people living with dementia. All carers discussed varying degrees of impact and how this altered between interviews with the changing restrictions.

*Reduced social interaction and a deterioration of dementia symptoms*

Across time points, participants saw an increased speed of deterioration in the person they cared for, which they perceived as being linked to the changing and/or reduced access to support and contact from family members and peer groups.

“…she [nurse] noticed how [partner] had deteriorated during the lockdown.” (Maya)

Aran discussed how they had noticed such changes over the two interviews and why they felt this was:

“It’s got worse I think over the period…I put that down to: one she would just be getting worse anyway regardless because it’s degenerative…two, I think it comes down to complete sort of boredom and everything on her side because she’s literally been a prisoner in her home” (Aran).

Some participants acknowledged that there would be deterioration over this period due to the dementia; however, they felt that the reduced social interaction due to COVID-19 restrictions may have sped this deterioration up and negatively impacted on the wellbeing of the person living with dementia. This deterioration induced negative feelings for carers.

*Sudden changes in formal support impacted negatively on wellbeing*

Due to restrictions, key supports (e.g. social services, healthcare professionals from the NHS , daycare groups), which carers relied upon, were suddenly withdrawn, significantly reduced, and/or altered for people living with dementia; this impacted negatively on the wellbeing of both the person living with dementia and the carer. Across both interviews, and even as lockdown restrictions were eased, Nina highlighted the loss of a partnership with healthcare professionals when supporting her mum’s healthcare needs, and Rhea discussed delays in assessments to access much needed support for their partner’s rapidly deteriorating dementia:

“when mum had a health problem, the leg ulcer, I found it very reassuring that we could see the nurse once or twice a week…when that was changed [due to COVID-19]…I felt I didn’t even have that partnership” (Nina).

“I have had no assessment from social services or anybody…I haven’t had an assessment of needs or anything like that” (Rhea).

The reduced support from community assets (Windle & Bennet, 2011) meant increased responsibilities for carers and potentially a financial burden. The stopping of support from day care groups also impacted upon carers. For example, across both interviews Sarah spoke about having to take on responsibilities previously provided by a day care group prior to the COVID-19 pandemic and how this continued when restrictions were lift as such supports did not reopen. This additional responsibility caused increased stress:

“…the social aspect because my mum’s quite a sociable person anyway…[dementia groups] just disappeared over night… I’ve tried to fill in a little bit for that…that was a stress on me…” (Sarah).

For Aran, a support group for their parent meant piece of mind for two days a week and time away from their caring role. However, as the support group temporarily closed (again, this was across both interviews), Aran had increased caring responsibilities as they tried to fill the gaps left by this:

“…she went to the [support] group…that was two days a week where you could almost put it to the back of your mind…that’s two days that we don’t have to think about it…you can sort of relax a bit more knowing that she’s doing something, being taken care of…” (Aran).

The loss of support meant that some carers felt overwhelmed with their additional responsibilities and the lack of a break from their caring role:

“Because of the Covid, because of that there’s no release, release might be, release care might be better than respite because there’s no release…but, err also I know if it were possible if there were places, I wouldn’t mind the hospice because they do respite” (Amy)

*Sudden changes in informal support provided by and for carers*

COVID-19 restrictions also impacted negatively upon the informal support structures of carers and the person living with dementia. For example, for some participants, restrictions (e.g., restricted visits behind protective screens and for limited amounts of time) meant that they were unable to see or provide their usual person-centred care for their family member living in a care home which was reported across both of their interviews:

“I feel helpless really…I want to go and be there, but we’re just not allowed…” (Sophie)

“It’s horrendous…when you’ve got a family and you can’t see them, they’re not allowed in your home and you’re not allowed in their home, it’s not pleasant.” (Maya).

Not being able to see and support their family member caused feelings of helplessness and frustration. It also raised concerns about being forgotten and worries of the person feeling abandoned:

“I hope he doesn’t think I’ve abandoned him” (Maya).

Participants were concerned that the person living with dementia would not understand that they were not visiting them due to COVID-19 restrictions.

In some cases, COVID-19 restrictions also took away the informal support carers were able to draw upon. For example, during the first lockdown they were unable to see family and friends:

“…obviously he doesn’t live with me or anything…So throughout lockdown I sort of didn’t have his support because he’d got the three children.” (Sarah).

“…She [mother] didn’t understand why she was forgetting things, breaking down crying and I'm just like well who can, who can I reach out to, my brother is not able to help me, no other friends or family can come in” (Helen).

In person informal support was vital for the wellbeing of carers prior to COVID-19, consequently carers found it difficult during lockdown not being able to have physical contact or draw on such support during this challenging time.

**Theme 2: Carer resilience: Adapting to COVID-19 to support their own wellbeing**

COVID-19 restrictions took away many social resources (e.g. health and social care services) carers used to support their own wellbeing. To address this, participants demonstrated their resilience as they adapted and utilised other ways of supporting their own mental and physical wellbeing. All participants spoke of the need for social support through COVID-19, even if this was not physical face-to-face support, as it gave them an opportunity to share the burden:

“…at least there’s somebody to talk to about it [by telephone] and somebody to have a moan and have a grumble…if you would have been on your own; one being on your own through COVID and two having to deal with that situation…Then I think that will be really tough on somebody” (Aran).

Participants spoke about the need for digital literacy skills to stay in contact with others and increasingly used messenger tools (e.g., WhatsApp) and video communication platforms (e.g., Zoom) to communicate with family and friends. Online social events provided positive experiences for most, bringing family and friends together during a time when they were unable to see each other face-to-face

“we’ve started doing these quizzes [carer and family members but not the person living with dementia]…that’s been very positive…it’s brought the family together more, and we’re actually seeing each other on these Zoom quiz meetings every week so, and we weren’t doing that before.” (Sophie)

“…lots of social media which is supportive not distracting, not necessarily discussing our problems.” (Rhea)

Many carers spoke about adapting to the changing restrictions and accessing digital tools which were new to them. These provided useful platforms to alleviate some of the carer’s isolation and worry about the person living with dementia, and provided a distraction from the carer’s current situation. Participants still utilised such tools even as lockdown restrictions were eased. However, some participants identified challenges with the need for digital literacy skills which they or their family member may not have. For example, Maya highlighted the challenge their family member living with dementia experienced:

“They say well we can do facetime, [partners] got severe dementia. So, facetime is no good for him…it doesn’t work with people with dementia.” (Maya)

Within second interviews, as participants spoke about COVID-19 restrictions easing, many also started to feel more comfortable with seeing others, and took the opportunity to meet family and friends face-to-face, which started to provide some normality and produced positive feelings:

“…when the sort of second phase of lockdown finished and you were allowed to go to restaurants. I’ve been out with a few friends…I was able to physically see people again and it feels much better now…” (Rhea).

Other participants spoke about keeping busy during lockdowns to provide a distraction from not being able to see the person they supported who was living in a care home. Care home restrictions meant they could not provide the regular support they usually did (these restrictions were in place across both interviews for carers), and participants found ways of trying to take their mind off not seeing their loved one:

“I’ve just kept busy, and I do miss him so I thought as a project during lockdown I would make hats and mittens for the homeless…” (Maya)

Physical activity was also an important positive strategy used to help people with their wellbeing. Participants spoke about using home workouts and/or being able to walk during the nice weather which helped to induce positive feelings:

“…literally we can walk out into a green space…we’re so lucky to be able to do that…there is the power of nature…that’s been very positive” (Nina)

However, not all participants had access to green spaces and there was concern about accessing such spaces during times of bad weather.

**Theme 3: Analysis of risk: safeguarding the person with dementia**

Carers discussed analysing the risk of their family member living with dementia contracting COVID-19 and how this fed into their decision-making process. Participants were fearful of someone passing COVID-19 on to the person living with dementia. For some carers, the fear of other people coming into contact with the person living with dementia and potentially spreading COVID-19 meant they took on additional caring responsibilities:

“…it would be sensible for me to... exclude her [mother] from the household and keep her away and for me to stay in the household…I’ve had little to no opportunity to escape…I literally haven’t had a day off since last July” (Nathan).

“I was having about 40 hours care and then I’m paying privately a cleaner for ten hours…then brought carers out. I stopped them coming because I thought it was a risk that I could cut out. There were more and more cases and I don’t know where the carers are going out. So I’ve been doing it all on my own.” (Patricia)

Other participants spoke about the emotional impact of safeguarding the person living with dementia from COVID-19. Some were avoiding healthcare services where possible due to concerns about this high risk:

“I kept her out of hospital again…it was just that anxiety. The ambulance service did say ‘oh we will take her to hospital if you want us to’…we managed to devise a plan that kept her out of hospital but she [ambulance staff] could see that I was quite anxious…I didn’t really want to take her…because I think it was a bit of fear as well in because I’d known these three people who were all sort of 70 and over who’d gone in with minor health concerns and all got COVID” (Sarah).

Carers discussed their changing views of risk across the first and second interviews. For example, one participant discussed reintroducing paid carers into their parent’s support circle due to staff taking more precautions and wearing PPE:

“Just recently now we’ve started to [re]introduce the carers because I’ve felt that the infection rate’s lower and the guidelines to the carers have been stepped up….so they’re always wearing face coverings…” (Nina).

Sarah discussed her changing view of risk across in their second interview. They felt that the impact of their parent isolating on the deterioration of the dementia outweighed the risk of catching COVID-19, so they felt they had to “throw caution to the wind” (Sarah):

“I know that’s she’s getting worse…I’ve kind of thrown caution to the wind a little bit in the sense of you know take the grandkids around, you know have her around for dinner, just do what you want” (Sarah)

**Theme 4: Thinking about the future with COVID-19**

All carers discussed their future in relation to COVID-19. Carers felt that the pandemic had created uncertainty for them, and many struggled to see an end. Participants spoke about their hopes for the future, but also the impact COVID-19 had on this hope.

*Uncertainty of the future*

COVID-19 was associated with uncertainty for the future. Most participants, across both of their interviews, were frustrated and frightened about the future with COVID-19. For some participants, they felt that the winter months meant further lockdowns and a higher risk of contracting COVID-19:

“…this is frightening, going into the winter months with COVID-19 knocking on everybody's door…” (Eve).

For others, not knowing when COVID-19 restrictions would end induced negative feelings. There was a feeling of dread, frustration, and fear as participants did not know when things would start getting back to normal and importantly, when they would be able to fully access their supports:

“It’s frustrating, nobody knows when it will end” (Amy).

“…fear of the future is quite debilitating” (Jenny).

For participants, whose family member was living in a care home, there was uncertainty about when they would see their family member, and concerns they may never see them again:

“…my major thought was that he’s going to die and I’m not going to see him…” (Maya)

“…are we going to get to see her. I'm sure we will but goodness knows…we don't know how things will go. And in lockdown, when lockdown ends. And what the home is going to decide to do…” (Sophie).

*Hope for the future*

For most participants, their hopes remained consistent across the COVID-19 restrictions they experienced. Their hope for the future meant returning to some form of normality. For those whose loved ones were in a care home, their hopes revolved around being able to regain regular face-to-face contact with their loved ones:

“The biggest hope for the future…is to be able to see him regularly” (Maya).

Some participants discussed having hopes for the future which involved regaining their “life” and re-establishing a normality:

“…a bit of normality coming into our life with the theatres opening and the ability to travel around a little bit and get into our little cottages and I don’t want anything else to be honest.” (Brian)

“I hope…we can get into a bit of a routine and she can start going to groups again. I don’t know when that will be…I hope that that lockdown will ease…I can plan sort of socialising myself. And having a bit of a life myself.” (Sarah).

However, the same participants also discussed how COVID-19 had taken away their hopes in other things, such as Sarah who spoke about their hopes for the dementia stabilising for their mother being “decimated” as they experienced accelerated deterioration:

“I was hoping that after she had this [deterioration in dementia] in February that some therapy…or some social interaction that she would, you know, improve a little bit…I think with COVID that just obviously decimated all those hopes…” (Sarah).

**Discussion**

This research provides a rich understanding and expands our knowledge of how carers’ experienced supporting a person living with dementia during the COVID-19 pandemic. Its use of multiple interviews across time during COVID-19 adds a unique understanding of the changing experiences of carers to a small field of literature. The results illustrated that during the height of restrictions, COVID-19 negatively impacted on the wellbeing of carers and the person they were supporting. It also led to increased uncertainty and the need for carers to manage the risk of the person living with dementia catching COVID-19. Carers demonstrated resilience as they adapted to COVID-19’s new and changing restrictions, and reported some positive experiences, such as becoming closer (not in proximity) to their family.

Our research supports and adds to the literature (Giebel et al.,2020a; Giebal et al., 2020b; Sriram et al., 2021) by highlighting how the pandemic, and the sudden changes implemented in response to it, negatively impacted on carers’ daily lives in several ways. COVID-19 restrictions prevented and/or reduced carers access to their usual community (e.g., family and friends, attending church or the gym) and societal (e.g., health and social care services) resources, which they would have used to support their own wellbeing, and which would have acted as a “release” for the increased burden and concern (Gilhooly et al., 2016). For example, essential needs assessments and GP visits were cancelled and difficult to access, which meant carers and the person living with dementia were not getting the support they needed and sometimes felt isolated. Where formal services, such as GP appointments, were still available, changes to make them more COVID-19 safe, such as using telephone appointments or only allowing one person in face-to-face appointments, were not always seen as being appropriate and compounded the additional burden already being experienced by carers. When support groups for people living with dementia were closed, carers had to take on additional responsibilities, which in many cases added stress and burden to the carer. Compounding this, was the impact of restrictions on carers, especially during the lockdown period, which prevented carers from accessing community resources, such as family and friends. Previous research has illustrated the importance of carers accessing informal support, such as that from family and friends, in positively enhancing aspects of caregiving and quality of life, and reducing caregiver burden (Lindeza et al., 2020). Our research highlights the need for careful consideration of the sudden withdrawal, or significant changes to access of services and supports which carers rely on for the wellbeing of themselves and the person living with dementia. Instead, support needs to be provided to ensure processes are in place which allow carers to access formal and informal support.

Many carers felt that people living with dementia were isolated during the pandemic and reported significant deterioration in the person’s cognitive ability. Research supports this and has identified that isolation and loneliness can speed up the progression of dementia (Curelaru et al., 2021) due to a lack of mental stimulation (Giebel et al., 2020a). This sharp decline could result in increased dependency on carers, and without access to their usual supports, would result in additional responsibilities taken on during the COVID-19 pandemic. For some carers, a combination of the rapid decline in the person living with dementia and not being able to access support meant they felt they were inadequately prepared and did not have the tools to provide the necessary care; consequently, some carers felt that they had no alternative but to consider moving the person into a care home. Our research has highlighted the need for greater acknowledgement of the support needs of carers and people living with dementia during any future lockdowns or times of social restrictions. Strategies to ensure that the person living with dementia has regular mental stimulation and is not isolated need to be developed, whilst ensuring the appropriate precautions are in place to minimise the risk of COVID-19.

The negative impact of COVID-19 extended to carers hopes for the future. Carers expressed a hope for regaining their “life” and some normality, whilst simultaneously feeling scared and frustrated by the uncertainty of when things would return to normal. Hope has been identified as an important psychosocial resource and can support wellbeing (Duggleby et al., 2009; Irvin & Acton, 1997). but the continued uncertainty of what the future would look like impacted negatively on carers’ hopes.

Alongside the additional responsibilities, reduced access to supports and services, and the negative impact on carers’ hope, was the additional concerns and considerations carers managed around the risk of their loved one catching COVID-19. Giebel et al. (2020b) and Sriram et al. (2021) both reported that carers had to make difficult decisions around protecting the person living with dementia. Carers in our research also had to make difficult risk management decisions as they reported concerns that they or others could bring COVID-19 into the living environment of the person living with dementia. Many carers weighed-up of the risk of the person living with dementia catching COVID-19, the negative impact of limited interaction for the person living with dementia, and accessing essential support to alleviate experiences of burden. This was illustrated with carers stopping access to healthcare services, and paid carers and family coming to the person’s home. Interestingly, the longitudinal methodology of this study enabled the research team to explore changing attitudes, for example, some carers only allowed paid carers back once they felt the care company and staff had taken the appropriate precautions to ensure the safety of their family member (e.g., consistently wearing PPE). Other carers gradually allowed additional family members to socialise with the person living with dementia as government guidance allowed it and they perceived the risk of transmission to be lower. In our study and others (Giebel et al., 2020b), carers making risk management decisions experienced additional stress and worry. Therefore, it is essential that clear guidance is available for families and the care sector to ensure COVID-19 safe interactions with those living with dementia. Care organisations also need to ensure that paid carers are fully trained and equipped (e.g., use of appropriate PPE) so that carers can feel confident and comfortable in allowing them to provide essential support.

As illustrated, carers were negatively impacted in several ways during the initial stages of the COVID-19 pandemic, but they demonstrated a great depth of resilience as they tried to negotiate, adapt, and manage their way through this uncertain and changing environment. Carers explored ways in which they adapted to COVID-19 and how they tried to mediate the additional physical and psychological strain. Across the themes of this study, carers predominately discussed utilising community (e.g. social support and participation) and societal (e.g. health and social care) resources (Windle & Bennett, 2011) to support their own wellbeing. For example, for some carers, as they were unable to access their community resources (e.g., family and friends) in their usually format (i.e., face-to-face), they adapted and made greater use of technology, specifically social media, to stay in touch with family and friends, and reported this as a positive experience as it helped to distract them and strengthen relationships with family members. However, carers raised concerns about the challenges the person living with dementia experienced when trying to use the same technology and, though this technology provides benefits, it does not necessarily replicate face-to-face contact. These opportunities and challenges have been echoed in similar research (Giebel et al., 2020a; Lindeza et al., 2020). Interestingly, and like Hanna et al. (2021), during COVID-19, carers in our study too illustrated there was less involvement of organisations and support systems which meant carers utilised other factors to facilitate their resilience (e.g., family and friend support, technology, use of PPE, lifestyle factors (e.g., exercise) and green spaces). This lack of support from organisations placed greater ownership on the individual, and further highlighted the need for care organisations and support systems to ensure they plan for ways of supporting carers and those living with dementia during periods of sudden change. Individual assets (e.g. psychological, biological, and material resources) were not frequently discussed across participants but this may have been due to the interview topic guide focusing more on community and societal resources.

Over the time of this study, care homes closed to visitors before implementing strict procedures to ensure the safety of their residents, including only allowing short, supervised visits behind a protective screen, and restricting the number of people who could visit; one carer likened these procedures to visiting a prison. Though carers acknowledged that the sudden changes in care home procedures kept their family member safe, they felt that staff could not provide the same level of personalised care as them. Not being able to regularly see and care for their family member resulted in feelings of helplessness, concerns of being forgotten, and fears that the person living with dementia would feel abandoned. Many of the restrictions implemented during national lockdowns, including limitations on the amount and length of visits, have now been removed (UK Government, 2022; Alzheimer’s society, 2022) and wider restrictions across the UK have also eased. Given the reported improvements in the wellbeing of the person living with dementia when family and friends have been allowed to visit care homes under COVID-19 procedures (i.e. social distancing, wearing PPE; Verbeek et al., 2020), and the negative emotional impact experienced by carers when not being able to see their family member, if future lockdowns were to occur, care homes should be supported to implement procedures which allow carers to visit their family members whilst keeping residents safe.

This research study benefited from the use of multiple interviews across time during the pandemic. This enabled the research team to explore changes in experiences and highlighted important results, such as changing views on risk management. Furthermore, we recruited carers across diverse caring circumstances (e.g., cohabiting, person living with dementia in their own home, person living with dementia in a care home) which has allowed us to draw common themes and share experiences of diverse contexts. However, there are possible limitations to this research. A combination of a small sample size and a heterogenous sample (where care is provided and potentially what restrictions carers’ experienced at the time of their interviews) may mean the themes of this study are not as rich for one specific group based on where care is provided and the restrictions experienced. Additionally, carers were recruited through carer organisations and support groups which may mean a specific group of carers were recruited which already had access to social support. This may mean that the voices of those lacking support and potential groups who are not well represented within research were not included. Future research needs to carefully consider whether they wish to focus on a specific carer group, which are specified on several areas, including where they provide their support. Focusing closely on one group may support the development of specific recommendations for this group. Furthermore, recruitment strategies which seek out less represented groups in society need to be considered.

Conclusion

This study provided important insight into the challenges faced by carers during COVID-19 (e.g., accessing services and social support), the impact these challenges have had on carers’ wellbeing, and on the deterioration of dementia for their family member. Responses to any future pandemics or periods of social restrictions need to carefully develop and apply processes which allows carers and people living with dementia to continuing accessing support. Formal services (e.g., GP practices), care homes, and organisations also need to be supported to implement procedures to ensure safe environments. This will enable carers to remain visiting their family members and increase their confidence in accessing services, such as allowing paid carers to support their family member with dementia. Finally, carers demonstrated resilience as they adapted to sudden changes, and many drew upon tools available to them to ensure their own wellbeing and the wellbeing of the person living with dementia.

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