

QUALITATIVE PAPER

Impact of COVID-19 restrictions on carers of persons with dementia in the UK: a qualitative study

VIMAL SRIRAM, CRISPIN JENKINSON, MICHELE PETERS

Health Services Research Unit, Nuffield Department of Population Health, University of Oxford, Richard Doll Building, Old Road Campus, Oxford OX3 7LF, UK

Address correspondence to: Vimal Sriram, Health Services Research Unit, Nuffield Department of Population Health, University of Oxford, Richard Doll Building, Old Road Campus, Oxford OX3 7LF, UK. Tel: 0044 1865 743762. Email: vimal.sriram@dph.ox.ac.uk

Abstract

Background: informal carers provide the majority of the support for persons with dementia living at home. Restrictions imposed due to COVID-19 have had a profound impact on the daily life of the entire population. This study provides insight into the impact of these restrictions on carers of people with dementia living at home.

Design: qualitative semi-structured interviews.

Participants: purposive sample of carers who provide at least 10 hours of care a week for the person with dementia living at home.

Setting: UK.

Results: twenty-three carers were interviewed, and thematic analysis identified three main themes—Changes to daily life, impact on carer health and wellbeing and reduced support from health and social support networks. The results highlight the impact of restrictions imposed on daily life and routines due to the pandemic, wellbeing of carers, reduced social support, lack of access to health and care professionals and respite for carers. The restrictions have had negative consequences on carers' wellbeing, and they have experienced difficulties in accessing formal care services and respite care.

Conclusion: carers attempt to continue to provide physical, emotional and practical support for persons with dementia in the community throughout the COVID-19 restrictions. To prevent a future carer crisis, carers need better support systems including formal carer services, telecare solutions that work for them and additional support for respite, as the restrictions from this pandemic continue.

Keywords: dementia, Carer, COVID-19, thematic analysis, older people, qualitative

Key Points

- COVID-19 restrictions have impacted on health and wellbeing of carers of persons with dementia living at home.
- Carers of persons with dementia have difficulty in accessing formal care and respite services and need better support in using telecare solutions.
- It is important to support carers in the community now to avoid a future carer crisis as restrictions during the pandemic continues.

Introduction

There are an estimated 850,000 people with dementia in the UK [1, 2], and much of the care and support network for persons with dementia is provided by informal carers (family, friends and neighbours) [1, 3, 4]—hereafter referred to as carers. Persons with dementia prefer to live at home, and the majority of their care needs is met by their carers [5]. Carers may find caring satisfying and meaningful but providing care over a prolonged time can have a significant negative impact on the carer's physical and mental wellbeing, as well as on their social life and financial situation [6]. It is in this context that the COVID-19 pandemic unfolded in 2020. The World Health Organization declared the novel coronavirus (COVID-19) as a pandemic on 11 March 2020 [7] and Governments and health services across the world have sought to limit the impact of COVID-19 on health and society. Policy responses to COVID-19 are complex, context-specific and rapidly evolving, with different countries pursuing varying approaches to managing the pandemic [8–10].

In the UK, COVID-19 related restrictions varied from a national lockdown to local restrictions (often varying by region and between the four UK nations), to a tier-based system in England and a second national lockdown. These different sets of rules and poor communication around the rules led to only around half of adults in the UK in October 2020, saying they understood the COVID-19 restrictions [11]. A timeline of changes and restrictions within the UK in response to COVID-19 [12, 13] is given in [Box 1](#). COVID-19 restrictions have meant a rapid, often confusing set of instructions to be followed by the whole population, including persons with dementia and their carers.

Support for persons with dementia and their carers can be provided by formal support systems such as community health and care professionals, respite care centres and practical advice and support from charities, friends and family [3, 14, 15]. The care, support and help available to persons with dementia and their carers has already been reported to be more limited compared to before the COVID-19 restrictions [16]. During the COVID-19 pandemic, more people need assistance, health care and support staff may themselves be unwell or self-isolating, carers have been asked to isolate from their regular support systems and change their routine, and informal support systems (neighbours/friends) cannot be called-on due to social distancing and isolation guidance. Studies [16, 17] during the early part of the pandemic have reported on the effect of closures of support services on carers of persons with dementia. The restrictions imposed as a result of the pandemic have continued over months, and the cumulative effects of these restrictions on carers have not been examined adequately.

Study objective

It is to explore the impact of COVID-19 restrictions over a period of time on carers of persons with dementia living at home in the UK.

Ethics and patient and public involvement

This study is part of a larger study exploring carers' experiences of using assistive technology in dementia care and was approved by the University Research Ethics Committee (Reference number: R57703/RE001). As this study was conducted during the COVID-19 pandemic, we included questions on the impact of the pandemic, and the results are presented in this manuscript. All volunteers were provided with a participant information sheet (Supplementary file 1), and those who consented to participate in the interviews provided informed written consent (Supplementary file 2) prior to the interview. All information regarding the participants has been anonymised and participants are identified by a participant number within this manuscript. This study has a patient and public research advisory group that meets online twice a year. The group consists of two carers of persons with dementia and a person with dementia (all living in England). In addition to advice on research conduct, they also support dissemination of study results to other patient involvement groups and their wider networks.

Methods

Study design

The study described here is a segment of a larger sequential mixed methods study [18], which explored carers' experiences of assistive technology use in dementia care. Semi-structured interviews were conducted during the pandemic as part of that study. This yielded information on the experiences of the impact of COVID-19 restrictions on carers, which is reported in this paper.

This study used hermeneutic phenomenology [19, 20] as a qualitative methodology [21, 22]. Hermeneutic phenomenology deals with the way in which the world is understood and interpreted in relation to cultural, social and historical contexts. The method is designed to interpret meaning not just of stated facts but of understanding the lived experience in context and to then consider important themes and characteristics of the expressed facts. We have used the consolidated criteria for reporting qualitative research (COREQ) to report this study [23].

Recruitment

Participants were carers who participated in the mixed methods study, which consisted of an initial survey [24] on carers' experiences of using assistive technology in dementia care. For the survey, the inclusion criteria were: adult carers—family, friends or neighbours—providing at least 10 hours of care (e.g. shopping, leisure, personal care, finance) per week to a person with dementia who lives in their own home, with the carer living together with or away from the person with dementia. An email with the participant information sheet was sent to volunteers who gave consent in the survey to be contacted for an interview. From those volunteers who replied expressing an interest in participating, a purposive sample of participants reflecting variations in age, sex,

Box 1. Timeline of changes and restrictions within the UK in response to COVID-19

12 March 2020	Self-isolation measures for people with symptoms
16 March 2020	Social distancing measures of 2 metres introduced
18 March 2020	School closures
20 March 2020	Bars, restaurants and non-essential shop closures
22 March 2020	Shielding for the most vulnerable introduced
23 March 2020	First national lockdown
01 June 2020	Easing of lockdown restrictions
15 June 2020	Introduction of mandatory face coverings on public transport and hospital visits
12 October 2020	Introduction of tier level systems for imposing localised restrictions
05 November 2020	Second national lockdown
02 December 2020	Return to local tier-based restrictions
08 December 2020	One of the approved vaccines for COVID-19 rolled out
26 December 2020	Introduction of further restrictions in high-risk population areas
04 January 2021	Second approved vaccine for COVID-19 rolled out
06 January 2021	Third national lockdown introduced

living arrangements, rurality and relationship with persons with dementia was selected. The recruitment commenced in October 2020 and the final interview was completed in December 2020.

Data collection

Semi-structured interviews as part of the mixed methods study were conducted over the telephone due to the restrictions from COVID-19. The interview focused on caregiving experience and use of assistive technology. All questions were open ended and informed by an earlier systematic review [25], qualitative study [26] and survey [24] and confirmed as meeting the needs for answering the research questions by the patient and public advisory group. Because of the timing of when the interviews took place, a question on the impact of COVID-19 restrictions on caring for the person with dementia was included in the interview topic guide ([Supplementary file 3](#)), and this paper describes the results from these data. All interviews were carried out by VS. Demographic data were derived from the earlier survey responses and confirmed as being accurate with the participant at the start of the interview. The background of the interviewer as an Occupational Therapist and consequent interest in the research topic was discussed with participants. The participants were not known to the interviewer or the other authors before recruitment and trust in the interviewer was built by establishing rapport with the participants through email and prior to the telephone interview. Interviews lasted between 40 and 50 minutes, were audio-recorded, and later transcribed by a professional transcriber, verbatim with names of participants, names of the person with dementia and any towns/cities mentioned in the interviews pseudonymised to ensure confidentiality.

Data analysis

The data were analysed using thematic analysis following the process outlined by Lindseth and Norberg [27] and in our previous qualitative study [26]. VS listened to each of

the interviews and read the transcripts multiple times (first step). Line by line coding of each transcript was carried out using the software package NVivo 12 [28] (second step). The data analysis was ongoing throughout the period of data collection, and the interview guide was modified to allow focus of subsequent interviews on emerging topics. This ongoing method allowed earlier transcripts to be recoded to reflect new codes. All authors coded selected transcripts independently and met regularly to discuss and agree with ongoing data collection, analysis, interpretation and to generate themes. Data collection continued after 20 interviews to ensure no new codes were emerging and at the 23rd interview; it was concluded that data saturation was reached. Results from the data analysis presented in this paper, only relate to the impact of COVID-19 restrictions on carers, and was analysed from data collected for the larger mixed methods study [18] on carers' experience of assistive technology use in dementia. All the coded units were grouped into themes and underlying sub-themes (third step). Reflexivity (the examination of own beliefs, judgements and practices during the research process and how these may have influenced the research) [29] and integrity of the research process was maintained by all authors. The authors' experience and previous research with people with long-term conditions, including dementia provided the necessary expertise for this research. However, it is acknowledged that this experience may have influenced the coding and interpretation of the themes.

Results

Participant characteristics

A total of 52 participants were contacted by email and of those who responded and gave consent, 23 carers (18 women, 4 men, 1 non-binary) participated in the interviews. Participants' age ranged from 51 to 85, 11 of the participants were spouses and 15 participants lived with the person with dementia. [Table 1](#) provides further details of the participants.

Table 1. Participant characteristics

ID	Age range	Gender	Person with dementia is	Ethnicity	Living arrangements	Type of dementia	Years/months since diagnosis
1	71–80	Female	Husband	White	Living with person with dementia	Vascular dementia	2 years
2	51–60	Male	Mother	White	Weekly visits	Alzheimer's dementia	18 months
3	71–80	Female	Husband	White	Living with person with dementia	Alzheimer's dementia	3 years
4	51–60	Female	Mother	White	Living with person with dementia	Unsure	10 years
5	71–80	Female	Husband	White	Living with person with dementia	Alzheimer's dementia	4 years
6	61–70	Female	Mother	White	Living with person with dementia	Mixed dementia	8 years
7	81–90	Male	Wife	White	Living with person with dementia	Alzheimer's dementia	3 years, 6 months
8	61–70	Female	Mother	White	Living with person with dementia	Mixed dementia	1 year
9	61–70	Female	Husband	White	Living with person with dementia	Mixed dementia	6 years
10	61–70	Female	Mother	White	Daily visits	Alzheimer's dementia	4 years
11	61–70	Female	Husband	White	Living with person with dementia	Vascular dementia	3 years
12	61–70	Female	Mother	White	Visits every 3 weeks	Unsure	4 years
13	71–80	Male	Wife	White	Living with person with dementia	Fronto-temporal dementia	11 years
14	61–70	Female	Mother	White	Daily visits	Alzheimer's dementia	7 years
15	51–60	Non-binary	Friend	Other	Daily visits	Parkinson's Dementia	1 year, 3 months
16	61–70	Female	Husband	White	Living with person with dementia	Alzheimer's dementia	4 years
17	71–80	Female	Husband	White	Living with person with dementia	Vascular dementia	12 years
18	71–80	Female	Husband	White	Living with person with dementia	Lewy body dementia	7 years
19	51–60	Female	Mother	White	Living with person with dementia	Alzheimer's dementia	2 years
20	71–80	Male	Wife + Mother-in-law	White	Living with person with dementia (wife). Mother-in-law recently moved to nursing home	Behaviour variant fronto-temporal dementia (wife) + Vascular dementia (mother-in-law).	4 years (wife)) Unsure (mother-in-law)
21	51–60	Female	Mother + stepdad	White	Weekly visits (mother recently moved to nursing home)	Alzheimer's dementia (mother) + Vascular dementia (stepdad)	5 years
22	51–60	Female	Father	White	Daily visits	Alzheimer's dementia	4 years, 6 months
23	51–60	Female	Father	White	Daily visits	Mixed dementia	2 years

Themes

Analysis of the interview data revealed three major themes: Changes to daily life, impact on carer health and wellbeing and reduced support from health and social support networks—that reflected experience of carers of persons with dementia during the COVID-19 restrictions. Details of the themes and sub-themes from the analysis and illustrative quotes are provided in Table 2.

Theme 1: Changes to daily life

Participants had mixed perceptions of the impact of the restrictions due to COVID-19. Some perceived the restrictions as having made no change due to their previous daily lifestyle, whereas others were worried about the impact on themselves and the person with dementia.

Carers had to take extra precautions to avoid potentially infecting the person with dementia. This change to routine also meant they had to provide additional support to the person with dementia when formal carers could no longer come in to provide that care.

'I couldn't leave her [Person with dementia], and I wasn't comfortable with carers coming in who I don't know where they've been, who they'd been with' [Participant 13]

'She... the [professional] carer that comes in ... she wears full PPE [Personal Protective Equipment]. And also she, she kind of doesn't do any personal care

for my mum or cooking. I do all of that [now] because of, you know, the risk' [Participant 6]

Some participants felt that the lockdown and restrictions did not influence their daily life, either because they were able to continue to do activities that mattered to them or because they previously already had a restricted lifestyle.

'... because our life was quite restricted prior to the virus ... lockdown didn't have a huge effect on our day-to-day life. I was still able to pop out and get my shopping' [Participant 11]

'... we didn't, for a short while, we didn't meet anybody else. But that was not particularly unusual' [Participant 7]

Some carers were concerned about the person with dementia contracting COVID-19 and limited going out for social visits and friends/family coming in to see the person with dementia. Carers who lived away from the person with dementia chose to form protective 'bubbles' that continued to provide social and practical support. A support bubble (where one household can join up with one other household) during the restrictions meant carers, who lived away, could effectively become one household and act as if they all lived together) meant they could do things such as go round to the person with dementia's house, stay the night and travel together in private vehicles. They also did not need to socially distance from others in the support bubble.

Table 2. Themes and sub-themes with illustrative quotes

Theme	Sub-theme	Example quote 1	Example quote 2	Example quote 3
Changes to daily life		Not really . . . because our life was quite restricted prior to the virus . . . [Participant 11]	You know, I can order my groceries and they arrive, and everything comes to my door, whereas I would have, if I hadn't had technology, I wouldn't have been able to organise that [Participant 3]	. . . shared Lives, which is a one-on-one service, but the chap that takes him out is in Spain at the moment and then has to isolate when he comes home so that's not working out. And so at the moment we've, I have absolutely no support and help [Participant 17]
Impact on carer health and wellbeing	Physical health	I get what I need [exercise], but I haven't been able to get as much since March, obviously [Participant 3]	. . . obviously become much more . . . doing much more physical care and, and planning and thinking about things that you perhaps wouldn't have had to before [Participant 12]	We try to do things together, we do the gardening to get him motivated, we do do the gardening together but, I must admit, I can't do as much as I would like to do [Participant 1]
	Wellbeing	It was, it helped in a positive way because I felt very close to him, and we, we, we had a lovely close relationship 'cause I couldn't, I didn't have this mental pressure that I wanted to go out because I couldn't go out [Participant 18]	I think the most challenging thing being a daughter is the deterioration of my mother in front of my eyes, which is a long grieving process [Participant 14]	Physically and mentally, and health-wise I've got a major problem as a result of it, and then I have to look after me because if I don't look after me I won't be here to look after him anyway [Participant 17]
Assistance from support networks	Social support networks	One of my daughters lives quite near and she comes down if necessary. Well, she has come more often. When in March and April, when things were a bit dicey and food was difficult and things like that, she used to do the shopping [for us] [Participant 3]	it meant I couldn't go for some time and so the care role fell entirely on my sister and the other carers. For me, I suppose, obviously the extra precautions, I obviously . . . obviously very careful with Mum anyway, but got to be thinking about that really and, and contact, any contact I have with people [Participant 12]	I did have access to and used carer support groups but again that's all gone [Participant 9]
	Respite for carers	So, so the, perhaps though, for me there's, there's been a lot more, it's been, it's been very heavy because I've not been able to, kind of, organise, well, you know, day care, if you like [Participant 15]	we don't have any [support] at the moment with the virus and everything. Mum did have a friend that used to take her out on a Friday afternoon about once every three weeks . . . [Participant 19]	So that's [day care centre] been completely withdrawn and that obviously was a huge respite for us [Participant 23]
	Access to healthcare and care professionals	we also find it even more difficult to coordinate like talking to doctors or talking, trying to get in touch and try to get in touch with the occupational therapist to try and get him reassessed [Participant 23]	but as of yesterday she [formal carer] didn't come because she couldn't get here and in an emergency they wanted to send a complete stranger [Participant 4]	The only real change was I used to get a carer coming in for a couple of hours a week. I stopped that [Participant 13]

'If she gets COVID, then, you know, she's probably not going to survive it. So I have to protect her, don't I? I haven't got any choice' [Participant 6]

'So, we've, in these Covid times, produced a bubble including my mother' [Participant 14]

Reduced socialising and visits to a person with dementia also extended to when a person with dementia was hospitalised and the family were not allowed to visit and reassure the person, which in turn caused anxiety and stress for the carer.

'Because being in the hospital, we're not allowed to see him and that's causing me a huge problem' [participant 23].

Carers also had to continue to remind the person with dementia to wear a mask, which some resisted or simply did not understand the need for, and to maintain social distance.

'I have to remind him about keeping the distance and wearing the mask' [Participant 5]

Carers who were comfortable with technology use continued to use technology to communicate and stay in touch with the extended family and social networks where they could when regular face-face visits were not possible.

'As I say, we're both pretty adept with technology, so it's, it's, it's not something that's just come into our lives because of the COVID, I do not think so' [Participant 16].

'... Zoom or WhatsApp or Skype have had a tremendous help, otherwise the impact would have been significantly greater' [Participant 20]

Theme 2: Impact on carer health and wellbeing

Carers reported impact on their health and wellbeing as a result of providing additional support and care for the person with dementia as a direct result of the restrictions. This included increased physical help and support provided for the person with dementia and stress and anxiety from the deterioration in the health of the person with dementia during the restrictions in socialising and having to follow new rules.

Physical health

Carers of persons with dementia who needed physical assistance had to provide additional support and care due to the sudden lack of visits from formal carers who would usually provide support in the home. This in turn caused problems in the caring relationship or even injury to the carer.

'... and they withdrew all care and I was left looking after him. I couldn't even get [him] out of a chair, and so as far as what it's done is distanced myself from him' [Participant 17]

'I mean, I have picked him up and ended up in hospital because I had done the disc in my back... so I did it all... that was before we had the hospital bed, so I did it all' [Participant 18]

Wellbeing

Carers who could use technology were able to get reassurance that the person with dementia was safe, especially when they lived away from them.

'... but the fact that I could FaceTime dad and actually have eyes on him did help' [Participant 22]

COVID-19 restrictions introduced new rules in the UK for social distancing at 2 metres and for the public to wear facemasks in indoor public spaces. Carers thus had the additional anxiety of managing reactions of other members of the public towards the person with dementia, who may not necessarily follow rules on social distancing and wearing masks.

'... and it worries me that somebody is going to have a go at her, so, like I say, I've got the sunflower lanyard [wearing the hidden disabilities sunflower discreetly indicates to people around the wearer that they need additional support, help or a little more time] and hopefully that will be enough to, you know, and you would hope people wouldn't have a go at an old lady but you never know...' [Participant 19]

Carers who had to go out, for work or for shopping, were also worried about inadvertently infecting the person with dementia.

'... and I'm thinking, "When you bring something home, will it get to Mum?" So it's sort of constantly on your mind, "Will it get to her?" sort of thing ...' [Participant 4]

Carers were also anxious about the future and the care plans that they had wanted to be in place to support the person with dementia and how it affected their relationship.

'So, it's [changes due to COVID-19], it has absolutely destroyed the natural caring path that I would have, I would have maintained, I would have held with him' [Participant 17]

Carers reported problems experienced by persons with dementia in social activities as having an indirect impact on them. Carers had difficulties going out with the person with dementia due to the restrictions or having to take extra precautions at home. In some cases, the person with dementia had not been outside the home in months.

'... so I would take him. We'd had a ramp supplied at the front door so I could take him out in the wheelchair to the car, and then drive him around, but that had stopped... which means actually he hasn't been out since, well, about, just the beginning of March' [Participant 11].

Carers attributed the lack of socialising and in-person socialisation to a worsening in the condition of the person with dementia, which in turn had an impact on the carer.

'So it, it's made it more challenging in keeping Mum entertained' [Participant 19]

'I think it's accelerated her, her downgrade, definitely the lack of social interaction, and I think that's, that's been a, a huge impact on her' [Participant 2]

Theme 3: Assistance from support networks

As a result of the changing nature of restrictions, carers had difficulty in accessing their usual support networks.

Social support networks

Carers appreciated others within the wider social networks adapting to the needs of the person with dementia within the restrictions and changes from COVID-19, such as increased in-person visits (when restrictions were eased) to support the person with dementia and carer to compensate for them not being able to go out.

'But fortunately, my children were very supportive, and one or other of them would be here every weekend' [Participant 13]

Some carers did see the positive side to the changes in routines for themselves and the person with dementia.

'We've chosen to use it as quality time, not just with my mother but with my husband. We've, we've tried to turn it into a positive thing. This is an opportunity ...' [Participant 14]

'... because she [Person with dementia], we have to make sure she's got things to do because the, the various centres aren't, aren't open. So, she's, she's going out for more walks on her own ...' [Participant 10]

Carers, however, were also having to deal with persons with dementia unable to go outside, others from their extended social networks unable to visit and having to provide additional support to keep them occupied indoors, during the extended lockdown periods.

'She [Sister] would have her over for the afternoon about the same times, and we had a cousin who we used to go Sunday dinner to once a month, but unfortunately that's all gone by the by' [Participant 19]

Additionally, carers appreciated neighbours being mindful of social distancing rules, even when the person with dementia could not remember to follow them.

'And so, if they see mum and she goes towards them, they will step back from her ... They don't rely on her remembering that she's got to be six feet away ...' [Participant 14]

Respite for carers

For most carers, the visits to local day care centres and memory cafes were the time that they could have for themselves and was seen as a time for respite by the carers. Because of the changes in socialising rules and lack of support staff available to operate these centres, they were closed during the two national lockdowns in 2020. This for the most part had a negative impact on carer wellbeing.

'... but the going out for my mum is a breather from my dad [person with dementia] and he couldn't go to his day centre because it's closed, and mum didn't get any time to herself' [Participant 22]

'I did have access to and used carer support groups but again that's all gone' [Participant 9].

Access to health and care professionals

Carers felt there was a general lack of access to health and care professionals.

'I arrange [paid] carers if I've got appointments or I'm going to meet up with friends. That hasn't happened so much with the virus' [Participant 11]

'Everything [day care center] stopped, and so, you know, unless I provide 24/7 care there, there isn't anything else' [Participant 6]

Carers appreciated the use of technology for social support and communication with the person with dementia. However, a lot of the consulting and advice services for professional support were moved to telecare support, such as virtual consultations due to the COVID-19 restrictions,

which did not always work as intended and carers found it difficult to access services and professionals.

'Although, most of it's done over the phone now. And of course, you know, there was one, there's been several calls where you had to log into a website ... in order to have the face-to-face consultation, which has been really complicated. She would, there's no way she would have done that on her own' [Participant 15]

'Yeah, so, in fact, the detrimental side of it is with the medical services, the fact that everything is by phone, nothing is by video, and they haven't a clue what's going on. They can't, there's no body language, they can't read body language, they're just listening to voices and the standard of care has been, is, is now abysmal' [Participant 17]

Carers who could access support through formal carers felt that even if formal carers could come in to assist them with physical activities for the person with dementia, due to the prioritisation of care in the community for those at higher risk, the support available was limited.

'I get what I need, but I haven't been able to get as much since March, obviously ... I know where they are and I can contact them if need be, but they can't come here to support me' [Participant 3]

Discussion

This study sought to explore the experiences of the restrictions imposed by COVID-19 on carers of persons with dementia, and the results expand our limited knowledge on the impact of these national and locally enforced restrictions over a considerable period of time. Participants highlighted the negative experiences from these restrictions as well as the impact on their health and wellbeing.

In the UK, alongside testing, tracing and a vaccination program, the restrictions to movement, work, travel, shopping and daily routines have been the main mechanism of community and population level control of COVID-19. As with any large-scale change, the restrictions affected carers in different ways.

Anxiety, stress, burden and exhaustion are common among carers of persons with dementia [30]. During the restrictions from the COVID-19 pandemic, in addition to being aware of the changing nature of these restrictions and advice from the Government [11], carers had to continue to provide good care for the person with dementia, often when the usual support systems available is no longer accessible. Carers who relied on formal carers to help support the person with dementia had to weigh the risks of admitting others from outside their immediate household [17] or in most instances could not access these additional support services such as day centres and as a result they had to provide this additional care.

The COVID-19 restrictions have also exposed underlying weaknesses in the health and care system [31]. These restrictions and changes to lifestyle were introduced suddenly, and as health and care systems struggled to cope,

it had a negative impact on persons with dementia and their carers [32].

Use of technology and digital solutions has been recommended as a solution to support ongoing care for people with dementia in the community [33]. However, very little thought has been provided to telecare/telehealth literacy, how this vulnerable population would be able to use technology, the additional support required from carers in order to facilitate this and the potential to miss cues on physical aspects of health, with an over reliance on telecare. These findings echo those from another study [16] conducted at the beginning of the pandemic restrictions on difficulties encountered by persons with dementia and how carers have to step in to provide that additional support. Also, the genuine need for respite care [34, 35], benefits derived from some personal 'me' time by carers that was available through day care centres [16, 36], visits from other family members who could look after the person with dementia and substitute for the main carer cannot be replaced with telecare and technology solutions.

Carers did consider some positive changes due to the restrictions and appreciated the additional time that they could spend with the person with dementia and how this helped strengthen their caring relationship. Our findings show that while carers attempt to provide adequate care, with limited support from formal care services and changes to their daily life—over a prolonged period of time, sometimes stretching into months—their own health and wellbeing appears to suffer, sometimes leading to physical injury and increased anxiety for the welfare of the person with dementia. This is similar to other findings conducted during the beginning of the first lockdown restrictions [16, 37].

Interestingly, none of the participants in the study prioritised issues around personal liberty or the need for the person with dementia to be able to go out, meet others without restrictions and participate in social activities over that of protecting the person with dementia from the risk of infection. In fact, carers ended up providing additional personal care, to avoid the possible risk of infections from formal carers. However, when carers made a risk assessment and they accepted the risk of having formal carers [17] or the wider support network to come in to help the person with dementia at home, this did not always mean formal carers were available to support them or the COVID-19 restriction rules meant wider social support networks, they could usually rely on had to stay away.

Carers also did not overtly comment on their own risk of infection with COVID-19 and what if any impact this would have on their caring responsibilities, when unwell, towards the person with dementia, but they had to deal with the anxiety of managing the person with dementia and navigate situations that required wearing facemasks and social distancing when they went out.

Strengths and limitations

These interviews provided an opportunity to discuss the impact of lockdown restrictions over a period of time as

the restrictions unfolded. This enabled us to gain current perspectives on a rapidly evolving and important topic. All of the interviews were conducted over telephone due to the restrictions and this might have led to non-verbal cues and interactions being missed out. This study was part of a larger study, and only one open question was directed at participants on the impact of COVID-19 restrictions. We did not ask participants specific questions on the effect of being ill with COVID-19 themselves. Ongoing coding allowed us to use prompts to gather more information for this question and provide a richer picture of the impact of COVID-19 restrictions on carers. Despite our continued efforts, only one participant was from an ethnic minority group. It would be important to further investigate how carers from Black, Asian or other Minority Ethnic communities in the UK are impacted when caring for someone with dementia during the COVID-19 pandemic.

Recommendations

COVID-19 and the restrictions to keep the public safe are likely to remain in society for some time. The total cost estimate in response to COVID-19 by the UK government is an estimated £210 billion for measures announced until 7 August 2020 [38]. During that time, most of the attention has been on the economy and supporting services for the acutely unwell; this focus now needs to include those with long-term conditions such as persons with dementia and their carers and the support systems available to them. Healthcare providers, policy makers, third sector and special interest groups supporting those with dementia and their carers need to develop specific bespoke support systems for carers, based on our findings, especially as they continue under ever more stringent restrictions. These support systems could include targeted support for respite and additional support in use of telecare/telehealth solutions for those who may struggle with this. Adequate and urgent action is necessary now to avoid increased health problems of carers and increased institutionalisation of persons with dementia.

Conclusions

Carers face challenges in providing adequate care for persons with dementia and have faced additional difficulties during the COVID-19 pandemic that impact on their own health and wellbeing. The restrictions imposed because of COVID-19, and the response from health and care professionals towards the acutely unwell has overshadowed support to carers of persons with dementia, especially on formal care available at home and lack of respite for carers. As healthcare systems gear up to provide support for persons with dementia and their carers, closely working with carers and an understanding of their experiences is required to provide targeted assistance that is required.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

Acknowledgements: Authors would like to acknowledge support from the three members of the patient and public engagement and involvement panel set up as part of the carers' experience of assistive technology use in dementia study, for their comments on the interview questions and findings. We also acknowledge the contributions of all the participants in this study for their time and invaluable insight into the restrictions from the COVID-19 pandemic.

Declaration of Conflicts of Interest: None.

Declaration of Sources of Funding: This research is part of a DPhil in Population Health at the University of Oxford and received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

References

- Prince M, Knapp M, Guerchet M *et al.* Dementia UK: Update, 2014.
- Alzheimer's Society. Facts for the Media | Alzheimer's Society. Key Facts and Statistics on Dementia. 2020. <https://www.alzheimers.org.uk/about-us/news-and-media/facts-media> (22 December 2020, date last accessed).
- Pini S, Ingleson E, Megson M *et al.* A needs-led framework for understanding the impact of caring for a family member with dementia. *Gerontologist* 2018; 58: e68–77.
- Oyebode JR, Pini S, Ingleson E *et al.* Development of an item pool for a needs-based measure of quality of life of carers of a family member with dementia. *Patient* 2019; 12: 125–36.
- Winblad B, Amouyel P, Andrieu S *et al.* Defeating Alzheimer's disease and other dementias: a priority for European science and society. *Lancet Neurol* 2016; 15: 455–532. <http://www.thelancet.com/article/S1474442216000624/fulltext> (10 May 2021, date last accessed).
- Courtin E, Jemai N, Mossialos E. Mapping support policies for informal carers across the European Union. *Health Policy (New York)* 2014; 118: 84–94.
- World Health Organisation. WHO Director-General's Opening Remarks at the Media Briefing on COVID-19 - 11 March 2020. WHO Director-General Media Briefing 2020. <https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020> (22 December 2020, date last accessed).
- European Centre for Disease Prevention and Control. COVID-19 Situation Update for the EU/EEA and the UK, as of Week 50 2020. COVID-19 Situation Update 2020. <https://www.ecdc.europa.eu/en/cases-2019-ncov-eueea> (22 December 2020, date last accessed).
- Centers for Disease Control and Prevention. Your Health | COVID-19 | CDC. COVID-19 (Coronavirus Disease) 2020. <https://www.cdc.gov/coronavirus/2019-ncov/your-health/index.html> (22 December 2020, date last accessed).
- Robert A. Lessons from New Zealand's COVID-19 outbreak response. *Lancet Public Health* 2020; 5: e569–70. www.thelancet.com/public-health (22 December 2020, date last accessed).
- Fancourt D, Bu F, Mak HW, Steptoe A. Covid-19 Social Study - Release 23. London, 2020.
- Department of Health. Coronavirus (COVID-19): Guidance and Support - GOV.UK. COVID-19 Guidance and Support 2020 <https://www.gov.uk/coronavirus> (22 December 2020, date last accessed).
- The Health Foundation. COVID-19 Policy Tracker | The Health Foundation. COVID-19 Policy Tracker 2020. https://www.health.org.uk/news-and-comment/charts-and-infographics/covid-19-policy-tracker?gclid=EAIaIQobChMI8Jan3sLh7QIVeU7tCh1QnQBcEAAAYASAAEgKiMfD_BwE (22 December 2020, date last accessed).
- McCabe M, You E, Tarangelo G. Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. *Gerontologist* 2016; 56: e70–88.
- Pollock K, Wilkinson S, Perry-Young L, Turner N, Schneider J. What do family care-givers want from domiciliary care for relatives living with dementia? A qualitative study. *Ageing Soc* 2020; 1–14.
- Giebel C, Cannon J, Hanna K *et al.* Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. *Aging Ment Health* 2021; 56: 1281–88.
- Giebel C, Hanna K, Cannon J *et al.* Decision-making for receiving paid home care for dementia in the time of COVID-19: a qualitative study. *BMC Geriatr* 2020; 20: 333.
- Sriram V, Jenkinson C, Peters M. Carers using assistive technology in dementia care: an explanatory sequential mixed methods study authors. medRxiv 2021. <https://doi.org/10.1101/2021.04.08.21255110>.
- Laverty SM. Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations. *Int J Qual Methods* 2003; 2: 21–35.
- Figal G. Hermeneutical Phenomenology. Oxford, UK: Oxford University Press, 2012.
- Jentoft R, Holthe T, Arntzen C. The use of assistive technology in the everyday lives of young people living with dementia and their caregivers. Can a simple remote control make a difference? *Int Psychogeriatr* 2014; 26: 2011–21.
- Wallström S, Ulin K, Omerovic E, Ekman I. Symptoms in patients with takotsubo syndrome: a qualitative interview study. *BMJ Open* 2016; 6: e011820.
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International J Qual Health Care* 2007; 19: 349–57.
- Sriram V, Jenkinson C, Peters M. Carers' experiences of assistive technology use in dementia care: a cross sectional survey. *Res Sq* 2020. Preprint.
- Sriram V, Jenkinson C, Peters M. Informal carers' experience of assistive technology use in dementia care at home: a systematic review. *BMC Geriatr* 2019; 19: 160.
- Sriram V, Jenkinson C, Peters M. Carers' experience of using assistive technology for dementia care at home: a qualitative study. *BMJ Open* 2020; 10: e034460.
- Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci* 2004; 18: 145–53.
- QSR International Private Limited. NVivo version 12, 2020.
- Etherington K. Becoming a Reflexive Researcher - Using Our Selves in Research. London: Jessica Kingsley, 2004.
- Manthorpe J, Bowling A. Quality of life measures for carers for people with dementia: measurement issues, gaps in research and promising paths. *Res Policy Plan* 2016; 31: 163–78.

31. The King's Fund. The Road to Renewal: Five Priorities for Health and Care. London, 2021.
32. Alzheimer's Society. The Impact of COVID-19 on People Affected by Dementia. London, 2020.
33. Tousi B. Dementia Care in the Time of COVID-19 Pandemic. *J Alzheimer's dis* 2020; 76: 475–9.
34. O'connell B, Hawkins M, Ostaszewicz J, Millar L. Carers' perspectives of respite care in Australia: an evaluative study. *Contemp Nurse* 2012; 41: 111–9.
35. Tretteteig S, Vatne S, Rokstad AMM. The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature. *Aging Ment Health* 2016; 20: 450–62.
36. Strandenæs MG, Lund A, Rokstad AMM. Experiences of attending day care services designed for people with dementia—a qualitative study with individual interviews. *Aging Ment Heal* 2018; 22: 764–72.
37. Fancourt D, Steptoe A, Bu F. Trajectories of anxiety and depressive symptoms during enforced isolation due to COVID-19 in England: a longitudinal observational study. *The Lancet Psychiatry* 2020; 8: 141–49.
38. National Audit Office. COVID-19 Cost Tracker - National Audit Office (NAO). COVID-19 Cost Tracker 2020. <https://www.nao.org.uk/covid-19/cost-tracker/> (22 December 2020, date last accessed).

Received 11 January 2021; editorial decision 20 June 2021