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**Living with dementia during the
COVID-19 pandemic: coping and
support needs of community-
dwelling people with dementia
and their family carers**

**Research findings from the IDEAL
COVID-19 Dementia Initiative
(IDEAL-CDI)**

Gareth O'Rourke, Claire Pentecost, Eleanor van den Heuvel,
Christina Victor, Catherine Quinn, Alexandra Hillman,
Rachael Litherland, Linda Clare

Final Report

February 2021

Living with dementia during the COVID-19 pandemic: coping and support needs of community-dwelling people with dementia and their family carers

Research findings from the IDEAL COVID-19 Dementia Initiative (IDEAL-CDI)

Gareth O'Rourke^a, Claire Pentecost^a, Eleanor van den Heuvel^b, Christina Victor^b, Catherine Quinn^c, Alexandra Hillman^d, Rachael Litherland^e, Linda Clare^{af}

^a REACH: The Centre for Research in Ageing and Cognitive Health, College of Medicine and Health, University of Exeter, Exeter, UK

^b College of Health and Life Sciences, Brunel University London, London, UK

^c Centre of Applied Dementia Studies, University of Bradford, Bradford, UK

^d Department of Public Health Policy and Social Sciences, Swansea University, Swansea, UK

^e Innovations in Dementia CIC, Exeter, UK

^f NIHR Applied Research Collaboration South-West Peninsula

Correspondence to: IDEAL@exeter.ac.uk

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Main Messages

We interviewed people with dementia and carers from the IDEAL cohort to find out how the COVID-19 lockdown and continuing restrictions affected those living with dementia.

Some people with dementia coped well, while others coped with difficulty or were only just coping. The additional stress of COVID-19 exacerbated pre-existing coping difficulties. For many, social isolation increased anxiety. Some felt that lack of activity or lack of social contact caused a decline in their abilities to manage everyday tasks. Confusion about COVID-19 rules or difficulty remembering what to do led to anxiety when leaving the house. People felt that members of the public might not understand their particular needs.

While some carers felt they were coping well, others experienced stress when having to leave the home because the person with dementia might not be safe if left alone. Some experienced increased strain in the caring relationship compounded by an uncertainty about future availability of respite. Some were concerned about the complex health needs of the person with dementia alongside COVID-19 risk and lack of personalised information.

Both people with dementia and carers talked about the importance of access to safe outdoor space. People were anxious about how others would react or behave towards them regarding keeping a distance if they went out. Being connected to friends, family and wider community or support groups was important to help combat the effects of isolation.

People from BAME communities worried about their increased vulnerability to the virus. A lack of trust in Government guidance and in health care services added to their anxiety. However, some benefitted from strong community and faith group involvement.

What might be helpful for people with dementia?

- Reablement to help regain or maintain skills
- Personalised health advice regarding managing COVID-19 risk and the opportunity to ask questions
- Identification of people with dementia who live alone and an assessment of their needs

What might be helpful for carers?

- Needs assessment in regard to respite
- Novel forms of respite care that incorporate social distancing

What might be helpful for both carers and people with dementia?

- Access to COVID-safe outdoor spaces
- Continuation and expansion of 'just checking' services
- Support to get online and use the internet
- Communication and information through non-digital means
- Community COVID-19 'dementia awareness' initiatives

What might be helpful for people from Black and minority ethnic groups?

- Addressing concerns about their increased risk of COVID-19
- Directing information and support through existing community and faith groups

Executive Summary

Background

People with dementia living in the community are likely to be disproportionately affected by COVID-19 measures (Alzheimer's Society, 2020a). The Improving the experience of Dementia and Enhancing Active Life (IDEAL) programme (Clare et al., 2014) has been following a cohort of people with dementia and carers since 2014, and examining what enables them to 'live well' with the condition. The IDEAL COVID-19 Dementia Initiative (IDEAL CDI) was established to identify concerns and issues faced by people living with dementia and their carers as a result of the coronavirus epidemic and the strict social restrictions imposed in England between March and June 2020. The aim was to provide timely evidence to inform the development of policy and practice that will better address the needs of people living with dementia as we continue to live with COVID-19.

Method

We recruited people already taking part in the IDEAL cohort study. We conducted initial interviews during May 2020 (Study 1) and follow-up interviews with a sub-set of participants who were experiencing difficulty in coping at the time of the initial interviews 6 to 8 weeks later in June 2020 (Study 2). In July 2020 we interviewed participants from BAME communities who were already taking part in another IDEAL programme study (Study 3). We provided information about the IDEAL CDI study and took audio-recorded verbal consent to participate before conducting the interviews over the telephone.

Evidence from the IDEAL cohort about what helps people to 'live well' with dementia, and data from three online discussion forums for people with dementia and their carers, informed the topic guide for Studies 1 and 3. Interviews explored four main topics:

- Negative impacts: disruption to daily routines and emotional and social consequences of lockdown measures
- Coping strategies and support found to be helpful in mitigating negative impacts
- Unmet needs and additional support that might have been helpful in mitigating negative impacts
- Positive impacts or unexpected benefits

In Study 2, participants were asked about any changes to the difficulties they had described during their initial interview and what may have helped.

In Study 1 we interviewed 2 couples (person with dementia and carer), 9 individuals with dementia, and 9 carers; of these we followed up 1 couple, 4 individuals with dementia and 1 carer in Study 2. In Study 3 we interviewed 3 individuals with dementia and 5 carers. Across Studies 1 and 3 we gained information about 27 individuals with dementia, either from the person with dementia him or herself, or from a carer (two carers were jointly supporting the same person with dementia), and the 16 carers we spoke to also described their own experiences. In Study 2 we gained follow-up information about 6 people with dementia and 2 carers. All participants were living in England.

All the telephone interviews were audio recorded and then transcribed. We used content analysis to look for themes within and across interviews. We periodically retrieved data from three online discussion forums and compared these to our findings. The main resulting messages were produced following discussion with our Advisory Group and Alzheimer's Society staff and with input from our Patient and Public Involvement group.

Findings

We identified people who were coping well, people who were having some difficulty coping, and people who were only just coping. We observed features that seemed associated with coping well or having difficulty coping. Coping ability could improve over time.

Across Studies 1 and 3, nine people with dementia appeared to be coping well with minor or no difficulties, nine appeared to be coping with some difficulties and nine appeared to be having significant difficulties in coping. How well people coped did not seem to be related to severity of memory loss or other symptoms of dementia, or to the specific type of dementia

Participants who appeared to cope well all lived with others (usually their spouses) in reasonably harmonious relationships that were not strongly characterised by caregiving or receiving. They were more likely to be involved in local networks and communities of support that existed before the coronavirus and to have opportunities to contribute to supporting others as well as receiving support themselves.

Within the 'coping with some difficulties' group in Study 1, five of the six people with dementia were aged 75 or lower. They had concerns about how they would be able to adjust to using public space again, how dementia friendly the post-lockdown environment would be, and what support they would receive to enable them to adjust to changing levels of restriction. These concerns were less evident among BAME participants.

Where participants were 'just coping with significant difficulties', carers were generally stressed as a result of greater intensity of caring during lockdown and the lack of availability of respite care services. These participants, and those coping with some difficulty, were more likely to be recipients of new forms of community support started during lockdown.

Other factors that seemed to be associated with coping less well included:

- Deterioration in physical and cognitive abilities as a result of lockdown
- Missing face-to-face interactions, support and services
- Lack of personalised advice and information about their health and support needs in relation to restrictions and risk of developing COVID-19
- A lack of specialist support or services needed for reasons other than dementia care
- For people from BAME groups, a lack of information and support from trusted sources, compounded by lack of trust in health services and the establishment

Other factors that seems to be associated with coping well included:

- An optimistic and stoical attitude to life leading to acceptance of the situation
- Drawing on coping strategies developed to deal with getting a dementia diagnosis
- Receiving regular telephone calls from 'just checking' services, usually from voluntary agencies such as Alzheimer's Society, Carers UK and Age UK
- The use of online support and services during lockdown

The follow-up interviews showed evidence of considerable personal resilience and adaptability. Some participants felt their situation had improved and they were coping better. Some challenged their own fears about the risk of going out or concerns about breaking the rules. This became easier as restrictions were lifted, but was sometimes prompted by an essential need to go out, for example to attend a hospital appointment.

Conclusions

These findings have clear implications for ways of reducing negative impacts on people with dementia and their carers living in the community now and during future pandemics. However, as COVID-19 progresses the changing situation and local restrictions will mean there are other issues we have not uncovered.

Policy and practice suggestions

Access to personalised health care:

- Offering calls from a known health professional to discuss level of coping and personal health and care needs, if resources allow
- 'Dementia awareness' training for health care staff to recognise differences and changes in coping during COVID-19
- Improved links between dementia care and other local systems of formal and informal support
- Promoting links between primary care and BAME community leaders to identify novel ways to engage with people from minority groups

Maintaining mental and physical well-being:

- Maintain existing 'just checking' services and further develop capacity
- Use existing sources of local knowledge to target checks for people living with dementia who live alone
- Relaunch or refresh dementia friendly communities with local solutions to assist safe engagement in normal activities in line with current COVID-19 restrictions

Support for carers:

- Proactively contact individual carers to identify where support has been lost, offer proportionate assessments and respond to identified needs
- Develop new forms of respite care to support carers, such as overnight stays within support bubbles or physically distanced day care in public outdoor spaces

Information and support for all:

- Promote digital inclusion for people with dementia and carers
- Develop a blended approach to information and support for people with dementia using a variety of media such as online, print, TV, radio and face-to-face services
- Ensure that information and support services are dementia friendly
- Take into account cultural preferences for information content and delivery

Main report

Background

The Improving the Experience of Dementia and Enhancing Active Life (IDEAL) research programme (IDEAL study 2014-2019 and IDEAL-2 study 2018-2022; Clare et al., 2014) seeks to inform the development of interventions and initiatives aimed at supporting people to live well with dementia. IDEAL is centred on a longitudinal cohort study which recruited 1780 people living with dementia and included 1475 family carers of these individuals, and continues to follow their experience over time.

The IDEAL-2 COVID-19 Dementia Initiative (IDEAL-CDI) was a sub-study rapidly established to identify concerns and issues faced by people living with dementia and their carers as a result of the coronavirus epidemic. The aim of IDEAL-CDI was to provide timely evidence to inform policy and practice to better address the needs of people living with dementia during lockdown and as we emerge from it. An amendment to the ethical approval granted to IDEAL-2 by the NHS and Health Research Authority was obtained to enable IDEAL CDI to proceed.

IDEAL-2 is funded by Alzheimer's Society as a Centre of Excellence, and the IDEAL-CDI sub-study was approved by the Department of Health and Social Care and funded by National Institute of Health Research through the Older People and Frailty Policy Research Unit.

Three studies are presented: Study 1, Study 2 and Study 3.

Study 1

Method

Data collection for IDEAL-CDI was conducted via semi-structured telephone interviews and triangulated with data from online dementia forums.

Verbal consent for interviews was obtained and recorded prior to each interview. Interviews were conducted by a single researcher with most lasting between 25 and 35 minutes (min 20, max 70 minutes). All interviews were recorded and transcribed verbatim with the consent of the participant(s).

Four broad themes related to the coronavirus epidemic were explored during the interviews:

- Negative impacts in terms of disruption to daily routines and the emotional and social consequences of lockdown measures
- Coping strategies and support found to be helpful in mitigating negative impacts
- Unmet needs and additional support that might have been helpful in mitigating negative impacts
- Any positive impacts in terms of unexpected benefits

Data analysis of interview transcripts was undertaken following procedures described by Miles, Huberman & Saldana (2014), Strauss and Corbin (2008) and Flick (2009) and using NVivo software. Key themes and categories were identified, first within individuals and then across individuals. A data display was then used to provide a more accessible view of the

data set as a whole. From this the narrative account of findings that appears below was developed.

Findings emerging from analysis of interview transcripts were compared with issues being discussed by people with dementia and carers during the same period on three online dementia discussion forums. This allowed verification of our findings and a further layer of context and understanding. The three forums were:

- Dementia Diaries (<https://dementiadiaries.org/>)
- Alzheimer's Society Innovation Hub (<https://innovationhub.alzheimers.org.uk/>)
- University of Bradford Dementia Blog (<https://blogs.brad.ac.uk/dementia/>)

Recruitment and context

Existing IDEAL cohort participants who had previously indicated their willingness to be contacted with a view to participating in qualitative interviews were invited to take part.

Full lockdown measures were implemented on the 16th March 2020. On 1st June 2020 non-essential retail was allowed to re-open and local transport in urban areas was expanded, subject to strict conditions. On 13th June 2020 it became possible for single adult households to form a support bubble with one other household; there was also greater freedom for up to six people from different households, or a larger number of people from two households, to meet outdoors subject to remaining 2m apart. The initial interviews were undertaken between 13th May 2020 and 25th June 2020. At that time lockdown measures had been eased to allow unlimited number of times allowed outdoors to exercise per day and unlimited travel to engage in outdoor activities within England.

Findings

Participants

Twenty-two people (of 30 contacted) agreed to participate, all living in England. Eleven participants were people living with dementia and 11 were carers. We carried out 21 interviews representing a total of 19 'family' systems focussed around the person with dementia. See tables 1a to 1c for details of interviewees.

Levels of coping

Three distinct levels of coping could be discerned from the data:

- Coping well with minor or no difficulties (CW): 6 families
- Coping with some difficulties (CD): 6 families
- Just coping with significant difficulties (JC): 7 families

Levels of coping were determined from an assessment of the overall presentation of each person. Factors considered relevant to level of coping are shown in the Table at Appendix 1. It is important to note that no one person with dementia presented factors all of which fitted within a particular level of coping. Coping was categorised according to the severity and influence of individual factors balanced against the overall picture of how factors interacted.

Tables 1a to 1c set out the allocation of people with dementia following data analysis, showing key characteristics of each person. Although it is not possible to generalise from this small sample, some interesting observations can be made. In four of the six people with dementia categorised as 'coping well' no carer was identified, but in all six people with dementia the person living with dementia was not living alone. This reflected co-resident

relationships (mostly spousal) that did not appear to be strongly characterised by care giving and receiving, and relationships were achieving a sustainable reciprocal balance between the needs of carer and cared for. In contrast, five of the seven people categorised as 'just coping' were living alone.

Participants' underlying attitude and approach to life appeared to be significant in determining their level of coping. A positive attitude to overcoming difficulties and a degree of stoicism were often evident in the 'families' categorised as 'coping well'. Some people with dementia and carers drew on coping mechanisms they employed on receiving the diagnosis of dementia to cope with lockdown through a similar mind set:

You know, we... we're just very realistic about the whole matter really, but that doesn't... it... there's no influence or reflection on the virus situation and having dementia. We just keep on as we have tried to all along. (CDI04,PLWD,M,LWO,CW)

Well, this sounds very... really strange but [...] we've never met anybody that's got a relationship the same as us, we laugh at things [...] We can always find little things to laugh about [...] which we find gets us through with, with this COVID-19 and with [...] dementia. [...] We've had that all the time [...] You know, we've, we can laugh at anything. (CDI07,C,F,LWO,CW)

Being told we had to shield [...] it was a bit like them telling us about, when ... dementia, I mean. It's scary, no doubt about that ... but we've tried not to be [scared] and to carry on sensibly with our lives. (CDI18,PLWD,M,LWO,CW)

Other factors that appear to differ according to level of coping are the level and focus of increased anxiety felt during lockdown, the age of the person living with dementia linked to their expectations about occupying public spaces, and the type of community support experienced. More is said about this in the sections that follow.

There does not appear to be a strong pattern in the distribution of people with dementia across perceived levels of coping in relation to the scores on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) (a test for dementia). There may be a slight tendency to more mild dementia amongst the 'coping well' group, but that group also contains a person with dementia with a moderate MMSE score representing more severe dementia. The 'just coping' group contains the two people with the lowest MMSE scores in the sample representing moderate dementia, but also a high proportion of people with scores suggesting mild dementia. Similarly, type of dementia did not appear to be related to how well people were coping.

Study 1 participants by level of coping and characteristics

Table 1a Coping well with minor or no difficulties

| Study ID | Interviewee | Person Living with Dementia (PLWD) | | | | | | Carer (C) | |
|----------|-------------|------------------------------------|--------|--|---------------------------|---------------------------|------------------------|--|--|
| | | Age | Gender | Lives alone or with other(s) (LA, LWO) | Type of dementia | MMSE score and date (M/Y) | Ethnicity | Gender | Co-resident yes or no/Relationship to PLWD |
| CDI09 | Carer | 87 | F | Lives with other(s) | Vascular Dementia | 18 (08/19) | White: British | F | Yes/ friend or companion |
| CDI04 | PLWD | 88 | M | Lives with other(s) ¹ | Alzheimer's Disease | 27 (03/19) | White: British | No carer identified lives with or is cared for by spouse | |
| CDI18 | PLWD | 77 | M | Lives with other(s) | Dementia with Lewy Bodies | 27 (06/19) | Black British: African | No carer identified - lives with spouse | |
| CDI07 | Carer | 66 | M | Lives with other(s) | Alzheimer's Disease | 23 (04/19) | White: British | F | Yes/ spouse |
| CDI17 | PLWD | 74 | F | Lives with other(s) | Frontotemporal Dementia | 29 (02/19) | White: British | No carer identified/ lives with spouse | |
| CDI20 | PLWD | 79 | M | Lives with other(s) | Frontotemporal Dementia | 30 (08/19) | White: British | No carer identified/ lives with spouse | |

¹ PLWD is co-resident carer for a spouse who is also living with dementia.

Key to MMSE score indicating degree of cognitive impairment: 25 to 30 very mild; 20 to 25 mild; 10 to 20 moderate; 0 to 10 severe. See Appendix 2 for more details.

Table 1b Coping with some difficulties

| Study ID | Interviewee | Person Living with Dementia (PLWD) | | | | | | Carer (C) | |
|--------------------|--------------|------------------------------------|--------|--|---------------------------|---------------------------|----------------|--|--|
| | | Age | Gender | Lives alone or with other(s) (LA, LWO) | Type of dementia | MMSE score and date (M/Y) | Ethnicity | Gender | Co-resident yes or no/ Relationship to PLWD |
| CDI08 ² | Carer & PLWD | 73 | F | Lives with other(s) | Alzheimer's Disease | 22 (10/18) | White: British | F | Yes/ spouse |
| CDI10 ³ | Carer & PLWD | 57 | M | Lives with other(s) | Alzheimer's Disease | 26 (06/19) | White: British | F | Yes/ spouse |
| CDI05 | Carer | 84 | M | Lives with other(s) | Frontotemporal Dementia | 24 (12/18) | White: British | F | Yes/ spouse |
| CDI12 | PLWD | 67 | F | Lives alone | Alzheimer's Disease | 25 (08/19) | White: British | No carer identified/ lives alone | |
| CDI13 | PLWD | 72 | F | Lives with other(s) | Dementia with Lewy Bodies | Not available | White: British | No carer identified/ lives with spouse | |
| CDI15 | Carer (M) | 65 | F | Lives with other(s) | Alzheimer's Disease | 22 (10/18) | White: British | M&F ⁴ | Yes/lives with spouse x 4 days per week and friend x 3 days per week |

² Interviewed separately. ³ Interviewed together. ⁴ Lives with male carer 4 days /week and with female carer 3 days/week.

Key to MMSE score indicating degree of cognitive impairment: 25 to 30 very mild; 20 to 25 mild; 10 to 20 moderate; 0 to 10 severe. See Appendix 2 for more details.

Table 1c Just coping with significant difficulties

| Study ID | Interviewee | Person Living with Dementia (PLWD) | | | | | | Carer (C) | |
|--------------------|---------------------|------------------------------------|--------|--|--------------------------|---------------------------|----------------|------------------------------|---|
| | | Age | Gender | Lives alone or with other(s) (LA, LWO) | Type of dementia | MMSE score and date (M/Y) | Ethnicity | Gender | Co-resident yes or no/ Relationship to PLWD |
| CDI03 | Carers ⁵ | 92 | M | Lives with other(s) | Mixed Dementia | 22 (02/19) | White: British | F ⁶ | Yes ⁷ /spouse |
| CDI02 | PLWD | 72 | F | Lives alone | Vascular Dementia | 27 (11/19) | White: British | None identified/ lives alone | |
| CDI01 | Carer | 75 | M | Lives with other(s) | Vascular Dementia | 14 (11/19) | White: British | F | Yes/ spouse |
| CDI06 | PLWD | 85 | F | Lives alone | Mixed Dementia | 25 (11/19) | White: Irish | F | No/ daughter |
| CDI14 | PLWD | 60 | M | Lives alone | Alzheimer's ⁸ | 26 (03/19) | White: British | None identified/ lives alone | |
| CDI16 ⁹ | Carer | 84 | F | Lives alone | Mixed Dementia | 14 (11/18) | White: British | M&F ¹⁰ | No/sons and daughters |
| CDI19 | Carer | 96 | F | Lives alone | Vascular Dementia | 27 (07/19) | White: British | F | No/ daughter |

⁵ Primary and secondary carer interviewed. ⁶ Both primary and secondary carer are female. ⁷ Only the primary carer is co-resident with PLWD.

⁸ PCA Alzheimer's. ⁹ Interviewee is IDEAL consultee for PLWD. ¹⁰ Caring is shared amongst male and female family members.

Key to MMSE score indicating degree of cognitive impairment: 25 to 30 very mild; 20 to 25 mild; 10 to 20 moderate; 0 to 10 severe. See Appendix 2 for more details.

Negative impacts

Reduction in functional abilities

In eight of the 19 people with dementia, participants attributed one or more aspects of deterioration in their functional abilities to lockdown measures. This included: greater disorientation of time or place, or being more muddled or forgetful (4 people with dementia), attributed to loss of orientating routines; greater dependency in self-care (2 people with dementia), attributed to disrupted routines and carer doing more for the person living with dementia to avoid feelings of frustration; reduced mobility (3 people with dementia) attributed to walking less as a result of being confined to home or garden, comfort eating, and suspension of planned exercise or physiotherapy programmes; greater difficulty with speech, including word finding (2 people with dementia), attributed to speaking less and to fewer people.

Three people with dementia described greater difficulty in executive function (decision making and goal directed action) as a result of continuing lockdown. This included being less able to plan and organise activities for the day to come, and being less able to anticipate and control the onset of an episode of acute confusion. These experiences were always linked to a reduction in confidence in abilities:

Well, during the first week of the lockdown, I had a carer come to see me on the Saturday. Then I got a phone call on the Sunday to say that they wouldn't be coming [...] so that meant I couldn't have anybody to visit me to help me in the mornings to get my routine organised. That... I was all right for a couple of days, I managed quite well, but after that [...] I was getting very muddled, and I wasn't eating properly [...] I wasn't getting my food out in the mornings ready for the night-time meal, and I wasn't getting my washing done, or changing my clothes, or doing things like that.
(CDI02,PLWD,F,LA,JC)

The funny thing with me is I can feel it coming, I get a funny feeling in my head [...] and then I go... I go into sort of total confusion. And I've found the way I could get round it was if I get that feeling in my head I had to sort of [...] just sit with me eyes closed for [...] 15/20 minutes the fog used to lift and I would come back to normal again. But I found I was getting that more in my head. It used to be before the lockdown I had that feeling probably about once a month or every couple of months but then with the lockdown I was getting it every day and sometimes twice a day.
(CDI14,PLWD,M,LA,JC).

For some, the effect of the types of changes described above was an increase in the level of dependency, which in turn impacted on carers in the requirement to provide additional help with activities of daily living, more reminders and additional reassurance:

Well, we've sort of got into the routine that I get her evening medicines ready for her because by then... by the end of the day, she's very tired. Any effort is awful for her, so I've basically just taken on the role of getting her... I tried not to do for her anything that she can do for herself [...] to keep her going for as long as possible, but two mornings running, she came to me, and she said, "I can't remember where I keep my medicines". (CDI09,C,F,LWO,CW)

So... so yeah, her mobility is less because she doesn't walk anywhere. I do, when I can, try and get her to walk up the garden but even that is, you know, difficult to be able to get her to go outside. (CDI16,C,F,LA,JC)

But yes, the constant reminding father from the beginning of lockdown right through to now has been something that I've noticed. He... I think he's become more withdrawn and that's had a knock-on effect with my mother, who becomes very tearful. (CDI03,C,F,LWO,JC).

Changes in feelings and mood

The most common changes in mood or feelings during lockdown included a greater sense of social isolation (11 people with dementia), and feeling low in mood or depressed (7 people with dementia). Most participants (16) reported a heightened sense of anxiety caused by the coronavirus epidemic itself as well as associated lockdown measures and uncertainty about the future.

The experience of increased social isolation ranged from mild to profound. Perhaps unsurprisingly, those living alone were likely to experience it more acutely, especially if confined indoors. One such participant described her sense of loneliness as follows:

Well, when I look out the window the trees seem to be... there are beautiful big green trees outside my window ... and the trees seem to be in lockdown. [] Yes, there is nobody around. I look and wait... wait, I look for about five minutes and I don't see anybody. (CDI06,PLWD,F,LA,JC)

However, increased social isolation was also a feature of some co-resident families. It could be compounded where there were pre-existing difficulties in the relationship, or where the carer was experiencing a high level of stress associated with their caring role prior to lockdown. One carer described it thus:

[...] because I think of my life as a cage, then the cage has got smaller. (CDI01,C,F,LWO,JC)

More commonly, social isolation was experienced in terms of feeling less connected to peers, friends and family. The physical closure of specialist services such as memory cafés and suspension of dementia support and advocacy meetings was, in part, compensated for by a movement to online meetings. However, such facilities did not fully alleviate the sense of loss at being unable to meet with others. Whilst most participants reported having the means and know-how required to participate in online communities, this was not so for everyone, giving rise to fears of digital exclusion:

I used to be able to use a computer, but I... I couldn't... can't use it now, and I can't use telephones apart from the mainline telephone. (CDI03,PLWD,F,LA,JC)

Some participants reported what they considered to be a growing trend towards overuse of video-conferencing. This was sometimes accompanied by an anxiety that virtual meetings will become the norm for the future, with the additional benefits of coming together in one physical space increasingly unrecognised and placed in jeopardy.

I am so grateful for that service because that has kept me going really, but it does ... I do worry that it's too much sometimes and when things do start to change ...with the virus getting less and that, we'll still be Zooming instead of meetings like before. (CDI12,PLWD,F,LA,CD)

Social isolation was also experienced in terms of being unable to meet or participate within local communities and communities of interest, including faith communities. Once again, this was partially offset by a move to online activities. Those who did find ways of maintaining active links with such communities benefitted considerably, particularly where they were able

to contribute to the well-being of others as well as being the recipients of support themselves:

Yes, we... we... there were no social activities obviously after that but there were other developments which took place which swung into action also and we were very glad to see these developments and take part in them, and one of them is the fact that as church members... our church introduced the service online [...] religious activities and so on, it was virtual conferences, meetings ... and that was very interesting and very effective. (CDI18,PLWD,M,LWO,CW)

The most common expression of social isolation was the loss of physical contact with loved ones and the longing to embrace them again, especially grandchildren. Some participants mentioned an awareness that dementia had already started to rob them of the joy of knowing and enjoying their families, and a growing resentment of the additional lost opportunities caused by the coronavirus lockdown. Many were clinging to the hope that the end of lockdown would soon be announced. They commonly described a situation in which the effect on their well-being had become more damaging as lockdown had endured and which, for some, was becoming unbearable.

I mean we did go and visit our daughter in [town], her family, when I went up to the hospital there [...] so I have seen them all but... so we had a good laugh with them but not being able to give them a hug is terrible [...] And as you get older you... you think that your time for cuddling them is running out and you don't want to waste that time, really. (CDI05,C,F,LWO,CD)

In seven people with dementia, increased social isolation was accompanied by a lowering of mood. This was attributed to a variety of trigger factors, all of them linked to the conditions of lockdown. One participant felt that exacerbation of a long-standing depressive illness arising out of childhood trauma resulted from having too little diversion from negative thoughts. For some carers, the increased intensity and demands of their caring situation during lockdown contributed to a lowering of their mood (interacting with bipolar disorder in one person); for people living with dementia, the trigger was more likely to be loss of contact and peer support with others in their situation.

I'm bipolar so my mood goes up and down, and I find that going round to see my mum affects my mood greatly [...] Early on when it first started, and I couldn't go round to see my mum at all really, I did find it a bit easier for me because I didn't have to cope with being shouted at and the moods, and things like that. [...] And then... but then, you know, I feel guilty at the same time, so it's difficult. (CDI19,C,F,LA,JC)

I long to see my family and friends, I long to have the life I used to, be able to go out for coffee in the... the restaurants and meet with my peers at my dementia groups. (CDI12,PLWD,F,LA,CD)

Increased anxiety was experienced by nearly all participants, although the level and specific focus differed considerably from person to person. For those categorised as 'coping well' the level of increased anxiety was typically mild or moderate and primarily associated with the desire to avoid catching the virus themselves and concern that their loved ones would not be directly affected. This tended to be accompanied by anxiety about the infection and mortality rates and the suffering of unknown others; as well as a generalised anxiety about the negative effect of lockdown on society and the economy, both local, national and international.

Well, it will worry me if any of the family got it [...] But no, my... our children have... all seem to be fine [...] And luckily they've all got reasons for sort of surviving.
(CDI17,PLWD,F,LWO,CW)

I was worried, probably like everybody else I guess, I was worried, there was concern [...] I wasn't particularly anxious about my personal situation, I was... I was anxious about the global situation, if you like [...] I was worried about the disease [...] the effect on the population. (CDI18,PLWD,M,LWO,CW)

For those in the 'coping with some difficulties' and 'just coping' categories, anxiety was typically of greater intensity and felt with more immediacy in terms of potential threat to them. This was sometimes expressed as a greater awareness of the fragility of their situation be it within a caring dyad or as someone living alone with dementia. Concerns about the effectiveness of lockdown and its observance by the general public led some participants to alter their habits to avoid meeting others (e.g. by taking exercise very early in the morning), or by not going out even though they were not required to shield.

Well, it's only recently that there's been quite a few people around now, so I've changed my time of walking because too many people have started being together without keeping... keeping separate [...] And when I saw a group of teenaged boys being together, I actually held my hand out to them, asking them to stay away, you know, keep... keep some distance, and they did submit to me ... they did move.
(CDI10,PLWD,M,LWO,CD)

Yeah, but I... it's definitely had a reverse... a reverse impact on me because now I don't want to go out [...] I actually feel safer at home [...] You know when they brought in I could go out once a day for a week [...] and I went out and I thought this, this just doesn't look right to me. It just wasn't what I was used to. Because I'd been on the lockdown since the start and when I went out that day it wasn't normal for me.
(CDI14,PLWD,M,LA,JC)

Descriptions of this type and level of anxiety were particularly characteristic of the data provided by the people living with dementia aged 75 or lower. Some characteristics of this group are noticeable within the 'coping with some difficulties' category. This appears to be associated with a greater awareness of, and concern with, the risks associated with using public space. Two of these participants described unpleasant experiences in which officials (a policeman and a supermarket employee) demonstrated a lack of dementia awareness resulting in a difficult conversation. Others expressed fear that they would forget to observe social distancing rules and suffer social disapproval or sanctions as a result.

She's certainly getting... she's more anxious... and more frightened. She's frightened that she... she won't obey the... the rules [...] obviously that she'll forget the rule... rules, of the six feet and things, and...not touch any other person.
(CDI15,C,M,LWO,CD)

These types of experiences or anxieties may arise from a greater expectation amongst the people aged 75 or lower to be able to continue to use public spaces, and the need for them to negotiate new hazards in public as a result of the coronavirus epidemic. These participants reported a noticeable turn in their experience as the easing of lockdown was announced and implemented, with anxiety increasingly projected forward towards the 'new normal' and what it would mean for people living with dementia.

Additional demands and stress felt by carers

Carers reported a range of experience in relation to the coronavirus lockdown, some of which has been touched upon above. Interestingly, in four of the six people with dementia categorised as 'coping well' no carer was identified, but in all six people with dementia the person living with dementia was not living alone. This reflected co-resident relationships (mostly spousal) that did not appear to be strongly characterised by care giving and receiving, and/or relationships that were achieving a balance between the needs of carer and cared for such that the former did not feel it to be burdensome. In at least one of these relationships the person living with dementia was them himself the carer for his spouse. The following account captures something of the character of these relationships:

I can't really explain how we get through things, it's... we get on so well. We've been together for nearly 40-odd years so we know what each other are thinking. (CDI07,C,F,LWO,CW).

For other carers the additional demands and stress associated with their caring role during lockdown were considerable. Six reported problems stemming from the inability of the person they cared for to understand or retain information about social distancing measures and what was required of them. This often added to the need for constant repetition on the part of the carer and could give rise to what one carer described as 'little arguments' during which the person living with dementia questioned the validity of what had been said to them. In the most extreme example of this problem the fragile balance of a relationship in which there was a history of domestic abuse had become threatened:

I mean, I know, my daughters are wonderful... my other daughter lives in [town] and my grandchildren, and they just say, "oh, you shouldn't try and explain; don't try and argue, just go along with it", but I feel like screaming and saying, "when you're here 24/7", you know, "you try it". (CDI03,C,F,LWO,JC).

Whilst the closure of services had deprived people living with dementia with opportunities for social contact and peer support, the key effect on carers was to deprive them of precious periods of respite from caring. For some this was all the more difficult because it was accompanied by changes in the nature and intensity of their caring role, e.g. by assuming responsibility for personal care that had previously been provided by paid carers. Other factors impacting on carers included the curtailment of support by other family members (living in different households), and the need for some to accommodate both caring and paid work within home space that was arranged for the former but not the latter.

But that is my break. I mean, I'm not having it during the lockdown, but that is my break in my life is just the two and a half hours [...] at the Memory Club on a Wednesday. That is my break. Well, I can tell you, if you could see me now, the top of my head, right, I've got my skull and then my hair... well, my emotions are just trying to lift my skull up in a bubble, because I'm just... just imagine... just imagining to hold it all down. (CDI01,C,F,LWO,JC)

I think it's hard to sit here working if like [PLWD] is with me. I think... I don't know if it's probably easier for [them] to be with me not here [...] I worry about, you know, whether it... it feels lonelier to have somebody with you who... who's not really with you because they're working. (CDI10,C,F,LWO,CD)

For a small number of carers the differences and conflicts between their own needs and those of the person they cared for were brought into sharp focus. One carer described the problems arising from her own physical illness compared with her husband's need for strenuous physical activity every day. This had led to many difficult moments when she

could only hope that her husband would remember to social distance whilst too far away for her to remind him.

My husband's... the daily routine was to exercise the dog along the esplanade [...] but I had to knock that on the head fairly early ... in the lockdown because my husband can't remember that he's got to keep distance from other people, and although I was doing my usual kerb crawling in the car going along next to him, because I don't have good mobility so I can't walk very far, I was finding myself screaming at him, "stay away from that family", and that sort of thing, which was very unpleasant really because he hasn't got a clue why I'm... why I'm screaming at him. (CDI01,C,F,LWO,JC)

In another example the person living with dementia appeared content with the reduced social opportunities during lockdown because it reduced the pressure on her to speak with others (in the context of dysphasia associated with Alzheimer's disease). This perspective was not shared by her carer, who felt she was becoming a spokesperson for her partner and wished to avoid their relationship developing in that way.

But anyway, I don't really go out much on my own, because then I do get a bit frustrated, so [...] But I go to, you know, the shops or whatever, with [partner], and that's fine [...] and I could stay quite peaceful, if you like, yeah. (CDI08,PLWD,F,LWO,CD):

I'm not sure how ... what her thinking is but it wouldn't surprise me because I said, "look, we could do another walk somewhere" ... "oh, I don't know, what if I see someone, I don't want to, no, no, no, I'm better at home" and I'm sort of thinking, oh, I don't want that to become [...] So she doesn't have to be talking. That's my little worry in the background. (CDI08,C,F,LWO,CD)

For a number of carers, the coronavirus epidemic had made them more aware of the very fragile situation they were in and the potential impact of their being ill, not only for themselves but for the person for whom they were caring. This had prompted them to think about contingency plans:

And it gave me such a fright that I had to spend a whole week filling in the "what if" emergency plan for, you know, if something happens to me. (CDI09,C,F,LWO,CW)

Interruption of health services

Interruption of planned health services affected both carers and people living with dementia, adding to negative effects of lockdown. Some impacts were very immediate, and some have yet to be fully felt. Examples include suspension of tests and exploratory treatment of a newly diagnosed heart condition, cancellation of regular appointments to monitor long term conditions, discontinuation of physiotherapy and reablement following (pre-lockdown) fractured hips (2 people with dementia), suspension of daily visits by District Nurses to manage very unstable diabetes, alteration to cancer treatment to avoid immune suppression, and lack of availability of opticians, audiologists and chiropodists. Such interruptions are clearly not particular to people living with dementia and their carers but have added a further layer of difficulty to their experience of lockdown.

Mitigating factors

Health and well-being gains

A small minority of participants describe health and well-being gains in terms of a healthier lifestyle during lockdown, i.e. more exercise, healthier eating and reduced alcohol intake. This had a positive effect on their mood and outlook. A similarly small minority felt they had become more socially connected, albeit 'virtually' rather than through face-to-face contact. Slightly more participants expressed the view that lockdown had provided some beneficial retreat and respite from the pressures of everyday life and encouraged them to use time in new ways that they found enjoyable.

Such gains are clearly not exclusive to people living with dementia and their carers but were nevertheless partial compensation for their particular experience of lockdown and reflected hopes for something good emerging from it to be maintained into the future.

And I'm feeling much, much fitter and better with everything. It's... it's been so positive for me, yeah, as well [...] because you can't just go out walking anywhere, I had to make it an official thing to do [...] and I think, because I'm not drinking those... because I used to have three pints of lager on a Monday night ... because I'm not having any of them at all, I feel like I'm losing more weight as well. (CDI10,PLWD,M,LWO,CD)

We [do go] out everyday, exercise, walking, fresh air. More than before. In fact, I've lost half a stone. (CDI20,PLWD,M,LWO,CW)

I mean, somebody phoned the other day who has been in my address book, but we haven't been in touch for yonks [...] and that was such a tonic. We had a lovely old natter, do you know what I mean? [...] I enjoyed that so much, it was like she'd given me a treat [...] so I looked through my book, and I phoned somebody who I hadn't spoken to for ages, and, you know, I think that's quite a nice thing that's come out of it that, you know, people have had more time to keep in touch and everything. (CDI1,C,F.LWO,JC)

My house, my home, my bungalow is my world so I... it's neat and clean and tidy as it can be, probably OCD, but that's what keeps me going [...] I can't sit still so I have to be doing things all the time. (CDI13,PLWD,F,LWO,CD)

Having and making use of a garden

Many participants (11) reported the importance to their well-being of having and making use of a garden. This is perhaps unsurprising given the very good weather during the period of lockdown, and once again is by no means exclusive to people living with dementia and their carers. However, having use of private outdoor space adjacent or close to home does appear to have been a significant factor influencing level of coping and as such is noteworthy for future reference and application e.g. during any local lockdowns. To illustrate this the other way around, in all of the eight people with dementia categorised as 'just coping' the participants either did not have a garden or were unable to make use of their garden due to shielding or other issues.

Help and support from others

Families

It is important to note that whilst most supportive family members were sons, daughters or grandchildren (and their spouses), this was not exclusively so. In a small number of participants, siblings were an essential part of their support networks, as were a circle of

close friends that had come to be regarded as family by some participants. Families were cited as an important source of support in nine people with dementia, but some element of family support is identifiable in all cases.

Families tended to provide both emotional and practical support, the precise character of which was determined by proximity of the supportive family member to the household of the person living with dementia. Families living further away tended to increase contact by telephone and video calls to provide social interaction and welfare checks, as well as logistical support by arranging delivery of shopping. This included one son who set up a regular online shopping order and delivery from his home city in Scandinavia.

The common effect of such long and medium distance support was to maintain a sense of being a valued member of the family and reassurance that family members were safe and well. This was especially so where there was a visual element to contact through video calling. This benefit was additional to the practical benefit of having shopping delivered.

You see our... our family's a bit dispersed at the moment [...] and we felt anyway that it was important to keep in contact because [...] the worst that can happen very quickly. (CDI18,PLWD,M,LWO,CW)

I mean, my husband was given a new computer thing for... by one of our sons and so we can now actually talk to him on it [...] You know, with a picture in front of us, we're actually literally talking to each other [...] That's amazing really, isn't it? (CDI17,PLWD,F,LWO,CW)

Families who lived closer to participants also provided practical and emotional support. This could be via telephone or video calls or through visiting depending on their own circumstances. There appeared to be a high level of compliance to social distancing rules amongst the participants and their families, with visits arranged accordingly and mostly restricted to outdoor space (emphasising again the value of a garden). Many families appear to have been greatly conflicted between their strong desire to comfort participants through physical contact and the knowledge that to do so would place them at physical risk:

I'm going to see my son this afternoon, the one who lives in [town] So, we'll be [pleased] to see him, and we'll sit in the garden, stay well away. Yeah. And we have a... you know, we just have a cup of coffee, and come home. (CDI20,PLWD,M,LWO,CW)

I'll tell you a lovely one, [...] but I was brought round and left on the doorstep a darling little box, and inside the box was a tiny, weenie little bottle, and inside this little bottle was a little message - a message in a bottle, [...] and it said, "mum and dad, grandma, grandpa, we just want you to know how much we love you and we want to support you, and we're so sorry we can't give you hugs and kisses, but we're saving them up for later when we can". (CDI01,C,F,LWO,JC)

For some people with dementia family support involved taking on care arrangements that had been suspended at short notice due to the coronavirus epidemic. In the most acute example of this an extended family was required to organise themselves to provide daily care comprising a minimum of three visits, including management of unstable diabetes:

So, well, our problem immediately was that the carers stopped immediately at the lockdown. And my mother-in-law is also an insulin-dependent diabetic so the district nurse who was coming in daily stopped as well so from day one we had to put things in place so that was hugely stressful at the start. (CDI16,C,F,LA,JC)

The participant in this case felt strongly that her mother-in-law's status as a 'self-funder' of her social care had prevented them from accessing services that would have been available had she been funded by the local authority. The urgency of this situation was continuing to unfold as family members contributing to the care package were having to return to their paid employment after furlough or periods of leave or flexible working.

Family members also played an important support role in monitoring the well-being of people living with dementia and carers. This was sometimes made more difficult by their own circumstances (e.g. shielding) and the difficulties of physical visits. In one case, a daughter had become very aware of the increased tensions in her parents' relationship and had increased both physical and telephone contact considerably in order to support her mother (the carer) to identify and address early signs that her father (the person living with dementia) may be adopting abusive behaviours of his past. This was illustrative of the delicate balance and fragility of many caring relationships and the potentially serious impact of the coronavirus lockdown upon them.

Communities

Communities were cited as an important source of support in ten people with dementia, but an element of community support was identifiable in all cases. Support from local communities was mostly practical and came from a variety of sources. Pre-existing sources of community support took the form of good relationships with neighbours or friends living nearby expressed through mutual concern and support, as well as services provided by local retailers based on personal knowledge and accommodation of participants' additional needs as households containing someone living with dementia.

Support from faith communities also pre-existed lockdown and was of central importance in at least five people with dementia. This type of support was mostly spiritual and emotional (rather than practical) in nature, and reported by those participants who cited it in terms of mutual concern for, and aid to, others in their faith community.

New forms of community support had also emerged in response to lockdown. This was mostly delivered by local volunteers and involved shopping and delivery services as well as telephone befriending or support. It was not always clear how this type of support was organised, but often it was made available to participants through flyers put through their doors with local telephone numbers to contact. Supermarkets also provided a new form of community support through priority shopping times, and priority ordering and delivery, accessed through some kind of proof of circumstances (e.g. a shielding letter).

Although by no means applicable in all participants there did appear to be a tendency towards different types of support according to the level of coping. Participants categorised as coping well appeared to be more likely to draw upon pre-existing forms of community support and to obtain some additional emotional benefit by any opportunity for reciprocity that it contained. Those coping less well appeared to be more likely to draw on newer forms of support, mostly as recipients of services provided by local volunteers. This impression should be treated with caution but is worthy of further, more rigorous investigation with a larger and more representative sample. It may be an important factor in future considerations of how to develop inclusive forms of community support that encourage and facilitate the contribution of these deemed to be 'vulnerable'.

Yeah, we get on with our neighbours but it's usually them that come to me for help [...] we've had a natter and... and I wave to people across the road as I'm walking the dog or whatever [...] So we've got quite a good neighbourhood, they're there if we need them. (CDI07,C,F,LWO,CW)

I couldn't go to do my shopping and I lived on me own [...] the occupational therapist said she was getting in touch with social services because I would need shopping [...] and then it finished up these boxes every week, a box used to turn up. (CDI14,PLWD,M,LA,JC)

Services

A significant number of participants spoke of the value of 'just checking' services to them during lockdown. This was reported positively in eight cases and as an absence of support in three further people with dementia. Just checking services took the form of regular telephone calls, (weekly, fortnightly or monthly), to make a general enquiry as to participants welfare and invite a conversation thereafter, which could be purely social or could involve identifying and helping to meet support needs. Just checking services were mostly provided by voluntary organisations, including Alzheimer's Society, Carers UK, local carer centres and Age UK, and occasionally by staff working in NHS services. The positive effect of these calls on those that received them was very significant. They made participants feel less alone, helping to combat any sense of abandonment:

... the same as the other lady from the Memory Club, they ring up every now and again... one of them will ring you, and say, "how's things going?" and all of the rest of it, you know, and then if you've got any problems that come up during the conversation, you'll find someone will follow it up, and then ring you back, which all makes you feel good. (CDI01,C,F,LWO,JC).

Age Concern in [town], you know, we are... every... certainly every month we'll have a phone call from them saying, you know, are you okay, Mr [surname], is there anything we can do for you and whatever ... (CDI04,PLWD,M,LWO,CW).

Conversely, one participant who did not receive a just checking service felt it would have made a difference to her and others in her situation:

A chat on the phone, "how you doing today", you know, just talk, just talk for five / ten minutes, you know from Government... well, I'm saying Government but what, I don't know, wherever, that would have... that would do a trick for most people, to be honest. (CDI12,PLWD,F,LA,CD).

Other services appreciated by participants included community pharmacies that extended their repeat prescription collection and delivery services, and volunteers organised by councils to assist people who had received shielding letters. Some NHS services also appeared to have made particular efforts to continue throughout lockdown, most notably an Occupational Therapist from a cognitive rehabilitation service who continued to support one of the participants via telephone throughout lockdown, without which the participant felt they would have really struggled.

Gaps in services

Perceived gaps in services tended to be identified out of exploration of what participants had found difficult during lockdown rather than participants being able to name a specific service that would have made a difference to them had it been available to them. Three areas of service gap emerged from the interviews. Carer support, information and contact with primary care.

Carer support

As discussed above, many carers found lockdown very difficult due to increased intensity of their caring situation, changes in their caring role (sometimes incorporating tasks of physical

care that had previously been carried out by paid carers), and an increased awareness of the fragility of their situation and the potential impact of them being unable to continue in their caring role. Whilst just checking services provided by carer organisations helped to sustain some carers, a more fundamental need for carer assessment and the provision of some form of respite care went unmet.

Two very specific suggestions for filling gaps in carer support were offered. The first called for the availability of 'exercise buddies' able to partner with people living with dementia in exercise programmes that their carers are unable or unwilling to participate in. The second calls for greater availability of male carers and volunteers to provide men living with dementia with the company of other men where they would find this enjoyable (and naturally occurring opportunities are limited).

Information, and contact with primary care

There were mixed views about the quality and consistency of the general information about the coronavirus epidemic provided by government through the daily televised briefing and other media sources. Some participants found it helpful, others did not. However, there was a prevailing view amongst participants about the lack of detailed information relating to their own particular situation and that of their household.

Some participants did receive information that they considered to be personalised in the forms of texts or letters but most felt that the content was unclear or contradictory. Only one participant said he had received a shielding letter that 'explained everything'. This was linked to the experience of discontinuity in contact with GPs and other primary health care professionals, which one participant described thus:

I tell you one aspect which really I suspect what worried a lot of people, it certainly worried us, and that is that the kind of disappearance of the medical service providers [...] what I mean is these people were hard to come by [...] you tried to ring your doctor, your GP in that time you wouldn't be very successful, in fact you couldn't anyway because you had to ring 111. (CDI18,PLWD,M,LWO,CW)

The types of personalised information felt to be missing or contradictory were i) information about shielding and staying safe ii) information about possible symptoms of coronavirus and how to respond to them, and iii) the impact of social isolation on other health conditions. Other unresolved issues included absence from a priority list, and concerns about the increased needs of the person with dementia and the carer. As mentioned above, participants were looking for personalised information that addressed their individual circumstances, including their medical history and any long-term conditions or ongoing treatments. As such, their hope was that information would be delivered by someone they knew, and who knew them, in an interactive way that allowed for questions and discussion.

Dementia awareness and friendliness in post-lockdown planning

As mentioned above, there was a noticeable turn in the interviews about the mid-way point of recruitment as the easing of lockdown was progressed, with anxiety increasingly projected forward towards the 'new normal' and what it would mean for people living with dementia. This was a particular feature of the interviews with people living with dementia who were aged 75 or lower and perhaps a reflection of their wish and expectation to continue to make use of public space.

A gap relating to dementia awareness and friendliness as a feature of post-lockdown planning was identified. This requires further definition but areas for consideration are: training for officials supervising public spaces; clear signposting of continuing social

distancing measures; and training and support for people living with dementia to better enable their compliance.

Anyway, so I showed my badge and my Alzheimer's badge to a woman that was standing very close to Sainsbury's and I says I am... I've got Alzheimer's I said and I think I'm in the right time to go in because it's disability and she just looked me up and down, she says you've got to go to the back of the queue. [...] And I was... I was almost in tears and that's unlike me. I... and there's all these people around and I just went home [...] There's nothing wrong with my legs, there's... apart from dementia I'm fit and healthy and so she was judging me, she was judgemental. (CDI12,PLWD,F,LA,CD)

Study 2

Method

Follow-up interviews employed a similar conversational style to that used in the initial interviews. The conversation was opened with a general enquiry about current welfare and circumstances, and then developed by following up on themes emerging from participants' original interviews. Interviews lasted between 25 and 45 minutes.

The same procedure for obtaining informed consent to participate was followed prior to each interview. Participants were reminded to look at the Participant Information Sheet during the invitation call and invited to ask questions immediately before giving consent. Consent was taken verbally via a recorded telephone call. Interviews were audio recorded, transcribed and analysed using the same procedures as for the initial interviews.

Recruitment and context

We invited 1 couple, 4 individuals with dementia and 1 carer in Study 2, and all accepted; the couple were interviewed together. Only those from the 'just coping' and 'coping with some difficulty' groups were selected as it was felt these participants would provide the most valuable data in relation to potential policy and practice suggestions. These follow-up interviews provided information about 6 people living with dementia and 2 carers.

Interviews were undertaken between 28th and 30th July 2020. In the period between initial and follow up interviews lockdown restrictions were lifted significantly. On 4th July 2020 the hospitality sector was allowed to re-open, as were places of worship, subject to strict conditions. In addition two households of any size were allowed to meet in any setting.

Findings

Level of coping

The findings of the follow-up interviews revealed a significant improvement in three of the six people with dementia involved, such that they were considered to have moved to a higher level of coping. In one case movement was from 'just coping' to 'coping well'. Table 2 shows categorisation after initial interview (T1) and follow-up interview (T2).

Table 2 Level of coping – follow-up interviews

| Study ID | Just coping | Coping with some difficulties | Coping well |
|----------|-------------|-------------------------------|-------------|
| CDI01 | T1 & T2 | | |
| CDI02 | T1 | | T2 |
| CDI10 | | T1 & T2 | |
| CDI12 | | T1 | T2 |
| CDI13 | | T1 & T2 | |
| CDI14 | T1 | T2 | |

Taking advantage of the changing context

It is essential to note the change of context in which ‘coping’ took place at T1 and T2. Lockdown in England was significantly eased on 4th July 2020 and therefore participants were not ‘coping’ with the same circumstances at the time of their follow-up interview as at their initial interview. However, those who appeared to have improved in their level of coping seemed to have taken greater advantage of the easing of restrictions than those who had not.

In one person with dementia this flowed from their personal determination not to have her life interrupted any more than it already had been:

It’s got a lot better because I’ve decided I’m going to stop worrying about the... the virus, and just get on with my life, and I’ve been going out and doing things, fully protected, of course [...] But I’ve decided it wasn’t worth sitting indoors and worrying about it at my age, and with my condition. I thought I might as well enjoy what life I’ve got. (CDI02,PLWD,F,CW)

In another the participant was forced to confront his fears about venturing outside in order to attend a hospital appointment and found that things were not as bad as they had imagined:

Well, the thing was, I... I did feel like that until I actually got out to go to the hospital, and then when I got into the town, I... I know I wasn’t supposed to do it, but I... I went... I went to Marks and Spencer’s [...] Now, that was strange because it’s all one-way systems, and... and you’ve got to stand behind these... they’re like big circles on the floor. But once I worked that out, I thought, ‘well, this...this seems okay’, and then I thought, ‘well, I can do this’. But then the next day, I... I kept having an inkling that I wanted to go back into the town, and so I was actually fighting with myself to stay at home. (CDI14,PLWD,M,LA,CD)

The changed circumstances of lockdown benefitted all participants, even where there was no overall change in their level of coping. Being reunited with families and being able to embrace grandchildren was a particularly welcome development:

Well, I won’t say that situation has changed, to be honest with you. Just in the last week or two, you know, bearing in mind the COVID-19 thing, I have relaxed to the way I feel about it slightly, insomuch as we’ve met the family in the park on my husband’s birthday, and had a bit of a picnic, still socially distanced and everything, so that was rather nice. (CDI01,C,F,LWA,JC)

And then I had a bubble with my daughter. Seeing my daughter and hugging my grandchildren. (CDI12,PLWD,F,LA,CW)

The possibility of more substantive support from families had been important in helping some participants to return to greater normality. Reinstating a (pre-lockdown) pattern of extended stays with her daughter had helped to ease tensions in one participant's relationship with her spouse which had deteriorated during lockdown:

It was to sort of... put too much a finer point on it, it's to sort of a breakaway from my husband really ...you know, because things... things would be fine, we'd be alright and then he would get sort of grumpy so it would make it, you know, worse on both sides of...you know, conflicting...sort of thing. (CDI13,PLWD,F,LWA,CD)

For another couple, the requirement to work from home, which had been difficult for the carer at first, had developed into a welcome flexibility that enhanced the balance of work and caring to the benefit of their wider relationship:

I'm working at home sort of three... three days, but I'm going into work twice a week. So it's... it's feeling fine now. I think I've just got into it. I think I found it strange at first [...] there's a fine line between if you're working or not, and people are contacting you at any... any old time [...] But, no, it's ... I would say it's going quite well, and it's a nice balance of going in a little bit, but not... not totally. (CDI10,C,F,LWO,CD)

Reinstatement or continuation of services

Reinstatement of services was also a factor in stabilising and improving participants' situations. One person with dementia received an hour-long visit every morning to assist with organising for the day to come, which was reinstated in full; another received a weekly visit to help with going shopping or visit a café etc., but this was reduced to half of what was previously provided. The reduction was thought to be unrelated to the coronavirus situation but had exacerbated the negative effect of it on the person concerned.

Services that had continued or developed throughout lockdown were appreciated. The value of 'just checking' calls from dementia care or carer services was again evident. There continued to be a mixed experience of online services but those who had engaged cited their involvement in positive terms as something that was continuing to contribute to their resilience. One participant noted how increased online and telephone contact with others had helped to improve speech difficulties he had started to encounter during lockdown:

I actually think my speech... my speech doesn't seem to be as bad as what it was.[...] I've been doing a lot more Zoom... you know Zoom meetings. [...] so I've been doing a lot of those, and then plus I've got... the Alzheimer's Society was phoning me once a week. And now they've given me a... what I'd call a... a dementia companion, is it? ... that's who's phoning me this afternoon. Yeah, well, I... I think that... I think that's what's improved my speech, because I am starting to talk a lot more. (CDI14,PLWD,M,LA,CD)

However even those participants that spoke positively were conscious of the limits of online socialising and support:

My dementia family, as I call it, it's all done on Zoom and Lifesize. I don't... I don't actually see any of my friends. [...] I like people. I like to see people, I like to hug people, spend time with people, go for a coffee with people. Yeah, socialising with people and seeing them in the flesh, so to speak. (CDI12,PLWD,F,LA,CW)

Information

There was less mention of information in the follow-up interviews, particularly as a perceived deficit. Participants appeared to have a greater understanding of measures to combat the virus as a whole, although the introduction of local lockdowns and recent announcements of changes to restrictions, some made at very short notice, were unsettling for some. In one person with dementia, the provision of clear information relevant to personal circumstances had been a significant factor in the improved level of coping:

I... this...the last letter I've got, I can actually work on it; I can understand it.
(CDI14,PLWD,M,LA,CD)

Dementia awareness and dementia friendliness

Dementia awareness and dementia friendliness does appear to have been a factor in enhancing the coping of some follow-up interviewees. This presented in a number of different ways. One interviewee was prepared to identify herself as someone living with dementia, but only to people who she thought might be sympathetic:

I always carry the Alzheimer's Society badge which says I've got... have dementia and the other one about the... what is it? Sunflower one, you know? But I do not wear them. I carry them hidden in my bag. If I find that... I mean, I call it in the moment, I will have a look at people. I'd definitely go to them if they were wearing a Forget Me Not Friends badge, definitely. I know they know what I'm talking about. But I kind of look to see who... who would listen to me. (CDI12,PLWD,F,LA,CW).

Another could not be sure that it was her feedback to the Council that had produced a positive result regarding parking to enable easier access to outdoor space, but felt that it had at least contributed:

Okay, so it was part of the Council, let's put it that way ... and I said, "all you've done by closing those gates is give the general public, 95% of the general public two minutes' walk across the road from the large field that they can park anyway, so they just walk across the car park, and then the other 5% that are in positions like myself", and I told her my position [...] And the next day... now, this may be a total coincidence, but I don't know, the next day the gate was open. [...] it was a very nice lady, and she definitely took in and absorbed... you know, you know on the phone if somebody's listening. (CDI01,C,F,LWO,JC)

Finally, one further respondent found that sharing limited details about his situation in dialogue with a call centre worker helped to identify the best arrangement for him to be more digitally included through the purchase of a wi-fi package:

I phoned them up, because they... they kept sending me a message saying, "you've run out of data, do you want to pay extra and get more data?" [...] Yeah, and when I explained [some of my situation] it was a girl I spoke to, and when I explained to her, she says, "have you got a landline in?" and I said, "no", and she tells me, "have...have you ever considered"... I... I think they called it a router
(CDI14,PLWD,M,LA,CD).

Carer stress

Increased intensity of caring leading to a continuing high level of carer stress, coupled with the continuing unavailability of respite services, were key factors resulting in no improvement in coping in one of the follow-up interviews. These circumstances were not caused by the

coronavirus situation but its continuation was exacerbating them. The following extract captures something of the carer's daily struggle:

In fact, during the lockdown, you know, I have come to the conclusion... I mean, [PLWD] knows this, that I'm sort of, you know, right up to the top; I'm right full of it all now, and I am... I shall blow the top of my head off if I have any more stress, so I can't really cope with it a lot of the time anymore, and I just hear myself screaming sometimes, and I think, 'oh, my God, I'm turning into somebody I just don't want to be'. I'm fragile all the time. It's just I'm quite clever at putting a lid on it, but to be honest, if anybody said "boo" to me, I'd... well, I'd end up, you know, in a huddle on the floor, if you know what I mean. (CDI01,C,F,LWO,JC)

Progression of dementia

In two of the follow up-interviews participants reported deterioration in the cognitive state of the person living with dementia. They considered this to be a natural progression of the person's condition, unrelated to the circumstances of lockdown. However, greater difficulty in obtaining specialist support e.g. through Memory Clinics or dementia care professionals, was hampering efforts to adapt to changes or to slow further deterioration:

I'm walking a lot better than I was, but recently the Alzheimer's got a bit worse for me, and I've been getting very depressed. (CDI10,PLWD,M,LWO,CD).

Well, I mean, there's definitely been changes in [PLWD]. You know, that's... that's the other thing. I mean, I think he's had enough of this lockdown, and all the rest of it, but also, I mean, he can't explain to me half the time... time how he feels or why he's feeling like that, and from that point of view I do feel at a loss, and I feel very... you know, I lack the knowledge about the disease to know what way to go with things. (CDI01,C,F,LWO,JC)

Other participants expressed an awareness of living with a progressive condition and the course it is likely to take. For some, this translated into a sense of urgency and immediacy to make the most of daily living whatever the wider circumstances:

Yeah, it feels a bit like that, and also with the dementia, although I'm coping with it very well at the moment, I know it can go wrong at any moment. And I just want to live life while I can [...] to how I want to live. Once I've lost my memory, and... and I can't communicate with people or anything like that, it won't matter so much, but while I know what's happening in life, I want to just live it. (CDI02,PLWD,F,LA,CW)

Study 3

In the initial cohort of 19 'families' one person was Black British: African; all others were White British or Irish. Whilst this is broadly in proportion to participation by ethnic minorities in IDEAL, it was felt that a more focussed study was required to develop an understanding of the particular experience of people from BAME communities. This would include any specific issues or concerns confronting them. With this in mind, a parallel study was undertaken by researchers based in one of the IDEAL-2 partner universities.

Method

The same method and procedures were followed as for the initial cohort. Data were collected via semi-structured telephone interviews. Verbal consent was obtained and

recorded prior to each interview. Interviews were conducted by a single researcher with most lasting around 30 minutes. All interviews were recorded and transcribed verbatim with the consent of the participant.

The same conversational style and topic guide were applied. NVivo software was used as an aid to data analysis with coding to identify key themes and categories undertaken first within participant accounts and then across participant accounts. A data display was used to enhance visibility of the data set as a whole. From this a narrative account of findings was developed.

Recruitment and context

Existing participants already taking part in an IDEAL-2 study exploring ways of including the perspectives of people from BAME groups in research were invited to take part. All were living in England. Those invited had previously indicated their willingness to be contacted for follow-up interviews.

Interviews took place between 13th July 2020 and 22nd July 2020, a time when lockdown restrictions were easing but those who had been asked to shield were still advised to do so. Some faith groups had started to resume gatherings but none of the community groups had yet started to meet in person.

Some preliminary findings from the initial study were emerging at that time and prompts to explore potential similarities and differences amongst BAME participants were introduced.

Findings

Participants

Eight people (of 10 contacted) agreed to participate. Three participants were people living with dementia and five were carers. Three people were Asian British, four were Black British Caribbean, and one was the White British spouse and carer for her Caribbean husband. All were interviewed on their own. This yielded information about eight people with dementia, provided either by the individual concerned or a carer, and five carers described their own experiences. See Table 1d for details of participants and carers. Mini-Cog scores were available for five of the eight people with dementia; generally a score of below 3 is indicative of cognitive impairment.

Levels of coping

Levels of coping were determined through analysis of the content of each interview in terms of the family system focussed around the person living with dementia. Each family system was assigned to one of three levels of coping according to Study 1 categorisation of coping:

- Coping well (CW) with minor or no difficulties: 3 families
- Coping with some difficulties (CD): 3 families
- Just coping with significant difficulties (JC): 2 families

Taking account of the very small sample size of both studies, this categorisation broadly reflects that of Study 1. Whilst the same difference in levels of coping was evident, other features were less so; in particular the cluster of people with dementia aged 75 or lower who were 'just coping' in the initial study was not evident in the BAME participants.

Table 1d: Characteristics of BAME participants

| Study ID | Level of Coping | Interviewee | Person Living with Dementia (PLWD) | | | | | | Carer (C) | | |
|----------|-----------------|-------------|------------------------------------|--------|----------------------------------|-------------------------------------|----------------|---------------------------|-------------------|-----|------------------------|
| | | | Age | Gender | Lives alone or with other(s) | Type of dementia | Mini Cog score | Ethnicity | Gender | Age | Co-resident with PLWD? |
| 207 | Well | Carer | 85 | F | Lives with other(s) | Alzheimer's disease | 2 11/19 | Black British Caribbean | F | 73 | Yes |
| 209 | Well | Carer | 78 | M | Lives with other(s) | Frontotemporal Dementia Behavioural | 3 02/20 | Black British Caribbean | F | 75 | Yes |
| 121 | Well | PLWD | 57 | F | Lives with other(s) ¹ | Alzheimer's Disease | 0 02/20 | Asian British Indian | M Not in study | N/A | Yes |
| 211 | With difficulty | Carer | 81 | F | Lives with other(s) | Alzheimer's Disease | N/A | Asian British Bangladeshi | M | 44 | Yes |
| 106 | With difficulty | PLWD | 91 | F | Lives with other(s) | Unknown | 2 11/19 | Black British Caribbean | NONE | | |
| 201 | With difficulty | Carer | 79 | F | Lives with other(s) | Alzheimer's Disease | N/A | Black British Caribbean | F | 57 | No |
| 130 | Just | PLWD | 63 | M | Lives alone | Alzheimer's Disease and a stroke | 3 03/20 | Black British Caribbean | NONE | N/A | N/A |
| 236 | Just | Carer | 79 | F | Lives with other(s) | Alzheimer's Disease | N/A | Asian British Bangladeshi | M | 78 | Yes |

Negative impacts

Reduction in functional abilities

Five of the eight interviewees reported a deterioration in the functional abilities of the person living with dementia, which they attributed to lockdown. This included both cognitive and physical changes, the latter being attributed to a lack of exercise.

One person living with dementia gave a vivid account of increased disorientation and forgetfulness arising from the impact of COVID-19 on his life.

'I've been affected... I've been affected by it as if I've woken up in a different world, in a different universe. I've been through a nightmare of ordeals and I definitely feel that in some ways it's possibly affected me irreparably. [...]: Because I... I see one of the reasons why it's affected me without me realising it is that I haven't been active. So I've got aches... physical aches and pains. People talk about how important it is to be active but I spent so much time being inactive. And now I'm trying to kind of address the aches and pains by trying to move I'm finding it difficult to move as [easily] as I did before. So it's affected me physically in lots of ways, and mentally it's affected me even more because I think it's precipitated the brain problems I've got. You know, it really feels like my brain shuts down and starts up. My brain feels as if it shuts down and starts up again. Shuts down and starts up again. And it's always anxious about things. (130PLWD,M,LA,JC).

One carer made a more general comment, informed by her voluntary leadership role in the local community, about older people becoming more confused during lockdown. Talking about the community support she organised, check-in calls, food parcels and individually tailored support, she reported noticing some people were getting more confused.

Four interviewees reported difficulties associated with eating which developed during lockdown. In two people living with dementia, this appeared to flow from reduced appetite, but for two carers, it was linked to practical issues concerned with obtaining food, including the closure of restaurants and restricted access to supermarkets.

One carer remarked:

'because it was really difficult to get food; the queues were really long. I mean, in Camberwell and Peckham, and that, the queues were massively long, and older people can't stand in the queues for that long'. (201,C,F,LWO,CD).

Changes in feelings and mood

Changes in mood or feelings attributed to lockdown were similar to those described by participants in Study 1. Participants described a sense of social isolation (4); and feeling low in mood or depressed (3). These feelings affected both the person living with dementia and carers.

The families who were 'just coping' and those who were 'coping with difficulty' described the greatest sense of social isolation, describing how all the normal opportunities for social engagement had been taken away and sadness when visits to and from family members were not possible. Although some people, including a woman with dementia who was coping well had continued to make and receive visits from close family throughout the lockdown period.

For those who had been very socially active prior to lockdown the discontinuity had a very significant impact on aspects of life from which they derived much of their sense of well-being. In at least one account this had a very direct effect on mood:

‘we couldn’t engage with people, she just feels bored and frustrated, a little bit of depression, because you know, basically locked in the house, and you can’t go out’ (211,C,M,LWO,CD)

For one participant who lived alone lack of face-to-face contact with others was highly problematic and only partially compensated by contact via telephone:

‘sitting at home, feeling isolated and not having no one to talk to, really. Well, I’ve had people to talk to but feeling isolated, I’ve had people on the phone, but still feeling isolated’ (130,PLWD,M,LA,JC)

Similarly to those in the initial interviews, most participants (7) reported a heightened sense of anxiety caused by the coronavirus epidemic itself as well as associated lockdown measures and uncertainty about the future. Some anxiety related to the general situation and in at least one account was exacerbated by the television news coverage. This had resulted in the carer having to ‘ration’ the amount of news viewed by the person living with dementia to prevent it fuelling her anxiety.

For others, anxiety was more specifically linked to catching or spreading the virus. One interviewee, whose sister had become live-in carer for their mother during lockdown, commented on her sibling’s new sense of anxiety about leaving the house:

‘she’s frightened she might do something that kills her mum’. (201,C,F,LWO,CD).

One person living with dementia reported a new pattern of only leaving the house late at night for essential shopping because of his anxiety about coming into contact with the virus.

This type of anxiety sometimes extended beyond caring within families. One interviewee who worked as Director of a pensioner support centre spoke of her additional anxiety as a result of being ‘in the community’ doing this work:

‘I could die from doing all... I literally had a moment’ (201,C,F,LWO,CD).

Three families reported anxiety associated with the continuation of daily visits by paid carers during lockdown and the possibility of their introducing COVID-19 to the household. This was so marked for one family that they stopped the care agency visits. One sister took over full-time care of the mother who was living with dementia; whilst continuing her paid employment from home. This type of anxiety was only a very limited feature of initial interviews and seems to be more particular to BAME participants.

Additional demands and stress felt by carers

Two carers reported that the person living with dementia found it difficult to remember the guidance given about social distancing. One had taken away her husband’s bank cards so that he could not go to the shops as had been his regular habit before lockdown. The other carer spoke about taking a guiding attitude with her sister and paying extra attention to her needs which was also important to support her sister’s loss of regular activities outside the home.

Beyond this there was not the same articulation of increased carer stress as that emerging from Study 1 or 2 interviews. However, in at least one family the carer was demonstrably

struggling. This involved a husband caring for his wife with quite advanced dementia. The couple were supported by twice daily visits from carers. A planned increase in the care package, including the introduction of day care, had been put on hold by lockdown.

Problems with living environments

Some participants described problems with living environments during lockdown. No such reports were made in the Study 1 or 2 interviews. In two instances this involved being unable to access gardens, one because the key to the back door had been lost for some time and the Council had yet to resolve the issue, and the other because rails and a ramp were required for the person living with dementia to be able to use the garden safely, the council had been unable to help with the work and he was having difficulties finding anyone to do the necessary adaptations privately. One person living with dementia reported that he had no hot water because the electric heaters that Age UK had provided were too expensive to use.

Mistrust of public information and health services

Mistrust was also a feature of BAME interviews that was not readily apparent in Study 1 and 2 interviews. This included mistrust of news and official advice about coronavirus:

‘the Government’s like giving, you know... saying one thing, and then saying the other thing, and then mixing peoples up’ (211,C,F,LWO,CD)

The carer who rationed access to news coverage explained her rationale in this way:

‘Because it was just getting too much. Because it wasn’t a direct instruction, I’d just [say it] sometimes, so, like, because I’d say, “they are lying; they’re not telling you the full [part] the truth’. (211,C,F,LWO,CD)

Mistrust was also expressed in relation to care workers and towards medical interventions in general. One person who was living with dementia and other co-morbidities explained his reluctance to go to medical appointments:

“So there’s lots of appointments I should go to but I’ve just been too scared to go there because I don’t trust the process. And I forgot it, but there’s other projects... health issues I have to go for. But because I don’t trust the process, because traditionally, especially in my culture, it’s people’s... in my area Black people say well, you know what? If you go there, you most probably a goner. We won’t see you again. I know it’s like a bit... sounds a bit simple, but a lot of people really believe if you go to the hospital and you’re of certain heritage you’re going to be treated differently and you’re likely not to be seen again.” (130,PLWD,M,LA,JC)

Mitigating factors

Health and well-being gains

Two carers commented on enjoying spending more time with their partner during the lockdown. One commented on realising that she had been too busy prior to the crisis:

‘I’ve been home a lot more than I usually am, and I think it’s had a good effect on our relationship’ (209,C,F,LWO,CW)

‘In fact, I’ve quite enjoyed it...! And it’s made me realise I do too much, and I really need to calm down a bit’ (209,C,F,LWO,CW)

One carer described a dramatic improvement in her mother's physical and mental abilities which she attributes to the dedicated one to one care provided by her sister:

'miraculously, for Mum lockdown has been a good thing in terms of her overall development. I don't understand it, but having, I think, just [her sister] there talking to her, looking after her carefully, Mum has thrived'. (201,C,F,LWO,CD).

Having and making use of a garden and outdoor space

Only one BAME participant commented specifically on the advantage of a garden during lockdown but being able to use outdoor space, e.g. going out for a daily walk or being able to sit out at the front of the house, was important for some. The two families who were unable to access their garden during lockdown, both of whom were not coping well, found that aspect of their circumstances very frustrating.

Help and support from others

Families

Family support was very important to BAME participants, with five of the eight mentioning it specifically. For example, one woman living with dementia who was coping well with the coronavirus situation commented:

'I'm lucky, I think, because I have such good family support'
(121,PLWD,F,LWO,CW)

In two instances, a perceived lack of family support was expressed by people who were 'just coping'. A grandson had been living with one participant but she felt he had not provided the care and support she needed and hoped for. In another, the family was dispersed across the world and although there was a considerable amount of contact by video and phone calls, the lack of local family support was keenly felt:

'they're all scattered all around the world, so the pressure is... is much more heavier'.
(236,C,M,LWO,JC)

Communities

Two participants who were coping well did not appear to need community support although both kept in touch with friends. The remaining six participants had all received (and some had given) varying degrees of community support. Four of the BAME participants received community support in the form of meals delivered, and one was also getting help with shopping.

One carer was playing a very active role as a community organiser recruiting volunteers to support older people within walking distance with shopping and prescriptions and provide social support via telephone calls. She hoped that local friendships would form from this and people would continue to support one another. The possibility of reciprocal support was important for some participants; for example a woman living with dementia was in receipt of food parcels but was still donating to a food bank charity, and a man living with dementia said:

'sometimes people need to be supported more to be the best they can be and not recipients of services all the time.' (130,PLWD,M,LA,JC)

Faith communities were active in providing practical as well as spiritual support (unlike the interviews in Study 1 where they were focussed on the latter):

‘my church son just live around 10 minutes away from me, and he was really like... he was not my biological son, but he was more... he was just like a biological son. He would do all the running up and down at the shops, anything I... I need here he call me up to ask me if need anything separate from the food that we have delivered here, so... as I said, 110 [percent] support, right, left and centre’. (207,C,F,LWO,CW)

Another carer who lacked family support was a practising Hindu, and reported receiving practical help from both the Sikh temple and the Christian Church. Faith and faith communities were an important aspect of life for six out of the eight BAME participants.

Services

Similar to the findings of the initial interviews, half of the participants spoke of the value of check-in calls from Alzheimer’s Society and Age UK. A carer who was also responsible for a pensioners’ centre mentioned how her organisation supported people:

‘They really appreciated ringing people, and checking in on them’ [...] The feedback we got was that our... our older people really appreciated them caring for them. They would say, “oh, you care for me”, so happy... That someone was worried about them, and cared enough to ring them” (201,C,F,LWO,CD).

BAME participants gave a more wholehearted endorsement of the value of technology as a channel for contact and support than participants in Study 1 and 2. One participant who did not have wi-fi at home was nevertheless enthusiastic about using WhatsApp. No concerns were expressed about the possibility of services continuing online. One carer commented:

With church, because we have... I am on the [both my] phone, and on my tablet from Saturday to Saturday...! [*Laughter*], so that’s really... that’s why I think the time [goes] so much. I don’t have time to go in pity party because I’m on prayer line, and I’m on Zoom line with serving, so I do very, very good. (207,C,F,LWO,CW)

She also expressed concern for those who found it difficult to use technology:

“you know the sad thing what I think about this is a lot of seniors can’t be in touch because of they’re not... we was so slow in latching on to technology.” (207,C,F,LWO,CW)

Gaps in services

One man living with dementia pointed out a number of gaps in services that were not unique to him. One was the need for healthcare and other services to be more dementia aware:

‘Don’t put the onus on people with dementia to remember everything in terms of paying bills, in terms of doing so many things, where memory is the key factor’. (130PLWD,M,LA,JC)

He also highlighted the need for independent advocacy:

‘My social worker works for me but she also works for [...] Council, yeah? And so she’s got a conflict of interest. So I’m thinking like the conflict of interest is detrimental to the best interests of the client’. 130PLWD,M,LA,JC)

He also spoke about what he perceived as a lack of culturally appropriate services in the area in which he lives.

‘And also there’s nothing in my area for people of my culture. That is the sad thing. People of my culture fall through the... fall through the... the care needs because there’s literally nothing here for people of my culture. Before the breakdown I used to go to the Alzheimer’s place and I was the only Black person who went there, and there was nobody there like me. And I was never... I was never really invited back there.’ (130PLWD,M,LA,JC)

Cultural differences

The BAME participants reported broadly similar issues to the participants in Study 1 and Study 2 with a few notable exceptions, but some participants commented directly on the differences between their perceptions and behaviour compared with the majority population. For example one respondent felt his community was more responsible than the White community in keeping to the coronavirus restrictions:

even in East London, you know, we haven’t suffered that much because people listened to the regulation, they listen to the Public Health thing, because that’s why we are okay because we looked after each other, but over there because most population here is just mainly White, and because they can’t go to the pub, they can’t, you know, go to the other activities, like you know mass activities... You know, they... they feel like they were like, you know, in the prison, so they just went a bit wild. (211,C,F,LWO,CD)

Another participant carried a sense of social and cultural exclusion that he felt was largely not understood by the majority population.

‘A lot of people feel culturally excluded and... and just like... like... it’s like people just don’t get it, that there’s an issue, yeah? They don’t get that it’s a huge issue that is boiling up, and it’s like... people don’t understand how excluded some people feel and how some people really are.’ (130PLWD,M,LA,JC)

Reflection on the findings

The aim of this small study was to develop an understanding of how people living with dementia and their family carers in Black and South Asian communities have been impacted by coronavirus restrictions. This complements the work in Study 1 and 2 so that the diversity of needs and strengths of these communities can also be taken into account in developing guidance to reduce negative impacts on well-being. The work also supports the wider goal of the IDEAL-2 programme in gaining understanding of what living well with dementia entails and how it can best be supported (see Clare, Wu, Jones, et al., 2019; Clare, Wu, Quinn, et al., 2019; Martyr et al., 2018).

Levels of coping in this group were broadly similar to those found in Study 1 and Study 2 and also similar in that those who were struggling to cope had been having difficulties pre COVID-19 that were only exacerbated by the lockdown. Those who were coping well lived in a close positive relationship with their carer and this positive relationship continued and, in some people, improved during the lockdown period.

While many of the factors involved in living well with dementia during lockdown echo those evident in Study 1 there were some differences. One of the most striking distinct themes was the lack of trust in the medical and political establishment, also reflected in fear of infection in the wider BAME community. This was grounded in the realities of BAME groups being harder hit by the COVID-19 pandemic than others (Public Health England, 2020). This

lack of trust may have led to the higher level of anxiety in this group and also the more marked involvement with community groups and faith communities. This could be an indication to offer culturally relevant support (Department of Health and Social Care, 2016) to mitigate fears and stigma by investing in local third sector services who are more easily able to build trust with an ethnically diverse community (Public Health England, 2020). It is notable that the service most widely praised by respondents was the 'check-in' telephone calls which are run by third sector organisations. Faith communities are also an important resource for providing support for BAME communities. Community support was a key mitigating factor for most respondents. Similar to the findings of Studies 1 and 2, an element of reciprocal support was highly desired if not already present.

It is interesting to note that the BAME participants were positive and comfortable about online meet ups and online activities in contrast to the participants in Study 1. This may have been due in part to having more experience and need to connect internationally with family and friends even before COVID-19 restrictions made video calls the norm.

Overall Conclusions

The specific purpose of this qualitative study was to better understand the concerns and issues of people living with dementia and their carers during the coronavirus epidemic, with a view to informing changes in practice (Pickett et al., 2018) and providing guidance on how to reduce the negative impacts on well-being, mental health and relationships. The wider goal of the IDEAL-2 programme (Clare et al., 2014; Silarova et al., 2018) is to better understand what it means to live well with dementia and how this can be supported by wider society.

The findings described above can be applied to serve both of these goals. They suggest a set of policy and practice issues to be considered as we emerge from lockdown and in the application of continuing measures to combat coronavirus (e.g. local lockdowns). In doing so, they add to our knowledge of what constitutes living well with dementia, and how individuals might be supported to achieve that aspiration (Clare, Wu, Jones, et al., 2019; Clare, Wu, Quinn, et al., 2019; Martyr et al., 2018). We have collected rich data and have presented an in-depth picture of the experience of people with dementia during lockdown and following a period of eased restrictions. We will collect further qualitative data in another IDEAL study, 'Identifying and mitigating the individual and dyadic impact of COVID-19 and life under physical distancing on people with dementia and carers' (INCLUDE) to help understand these issues for people with dementia in greater depth.

Policy and practice suggestions for the 'new normal'

Our findings highlight the specific challenges faced by people with dementia during the COVID-19 pandemic, which are over and above the existing challenges experienced by people with dementia and carers (Alzheimer's Society 2020a, Alzheimer's Society 2020b).

The findings relate to several NHS policy documents:

- Dementia Wellbeing in the COVID-19 Pandemic (NHS England, 2020) - specifically around the focus on maintaining personalised care, staying safe and well, social prescribing and rehabilitation.
- Prime Minister's Challenge on Dementia 2020 (Department of Health, 2019) - linking to those stated aspirations for personalised support to meet diverse needs, access to a named GP with overall oversight of care, and adequate respite for carers.
- Joint Declaration on Post-diagnostic Dementia Care and Support. (Department of Health and Social Care, 2016) - in relation to the importance of attending to individual needs especially in times of change, and the provision of support and information that is personalised, flexible and culturally relevant.

A key finding of IDEAL-CDI involves the wide range of experience of people living with dementia and their carers, which has been translated above in terms of levels of coping. Whilst such typologies are inevitably theoretical and open to interpretation, the underlying fact of better or worse coping during the changes COVID-19 has imposed has been brought into focus. Different levels of coping also point to the need for targeted responses to support the recovery of people with dementia and improve capacity and access to respite care (Alzheimer's Society, 2020b) for carers in the aftermath of the first wave of the COVID-19 epidemic and in preparation for future phases.

Living with someone else appears to be an indicator of better coping, but only where co-resident relationships are harmonious and not overly characterised by the giving and receiving of care (Clare et al., in press; Rippon et al., 2020). In light of this, it may be possible to target recovery support at people living alone or with a carer who is already known to specialist carer support services. However, this is a crude indicator and it seems likely that local service providers will already have a more precise knowledge of who in their service area is likely to be in greater need.

A possible determinant of better coping appears to be a positive attitude characterised by a degree of stoicism (Lamont et al., 2019, Lamont et al., 2020). Participants tended to describe this in terms of a long established approach to life, which pre-dates coronavirus, but some described how they had drawn on coping strategies they had used at the time they were told of a dementia diagnosis. This is highly intangible at one level, but at the same time gives a clear message about the value of support to enable people to understand and deploy coping mechanisms best suited to them at the time they are informed of a diagnosis of dementia and for a period immediately afterwards.

This is reinforced by the findings of the follow-up interviews which reveal the capacity for resilience and adaptability that some people living with dementia continue to demonstrate as their illness progresses. This is often linked to a determination to live their lives as fully as possible for as long as possible in the face of their progressive illness.

The research findings are more helpful in suggesting a range of services and approaches that might support recovery as we emerge from lockdown and in preparation for any possible future measures. There has been considerable anxiety that people living with dementia will lose existing skills and abilities during lockdown due to lack of opportunities to use them. Functional decline linked to the coronavirus situation was reported in slightly less than half of the people with dementia, which is generally consistent with the proportion of people with dementia in IDEAL that perceive having impaired functioning (Martyr et al., 2019).

Often the decline reported was physical, rather than cognitive. Even where cognitive decline was attributed to lockdown this association was made tentatively in the context of any pre-existing trajectory independent of the circumstances of coronavirus. Nevertheless, it appears that personalised reablement programmes aimed at recovering mobility, speech and executive function to pre-lockdown levels could be of considerable benefit in a significant minority of the people with dementia (e.g. Clare et al 2019a; Clare et al 2019b).

This finding is reinforced by the findings of the follow-up interviews in which one participant reported that the reinstatement of a small amount of regular help had enabled her to regain her ability to organise daily routines; and another reported recovery of speech through opportunities for conversation via Zoom and with a newly appointed dementia companion.

Another aspect of possible service targeting involves the provision of information. Although improved information about available services and sources of support is a key policy area (Department of Health, 2019), the absence of information personalised to their particular culture or situation was perceived to be a gap by a number of participants and was often

linked to a discontinuity and for some a lack of trust in their relationship with primary care professionals. This suggests a need to develop systems and practices that offer at least a degree of continuity with familiar and trusted primary care professionals for those in greatest need; which may in turn serve as the channel for personalised information to be provided in an interactive way.

Whilst acknowledging the difficulties of achieving this at a time when all health services (indeed all public services) are likely to be fully stretched, the potential benefits in terms of well-being, avoidance of risk and inappropriate use of alternative services must be considered. Being in receipt of better information appears to be a feature of better coping as revealed by some follow-up interviews.

The research shows that carers have played a leading role in the implementation of measures to combat coronavirus and have been amongst those most negatively impacted as a result. Caring inevitably places a heavy demand on the resilience of carers but if we are to take the experience of carers in the IDEAL-CDI study as typical it is likely that many carers will be close to the limit of their ability to continue caring. This was apparent at both initial and follow-up interviews for carers experiencing the greatest difficulty.

There appears to be an urgent need for a highly pro-active approach to supporting carers as we emerge from lockdown. This might involve contacting carers individually or via established carer forums or channels to offer proportionate assessments and relevant services in response to identified needs. This includes the need for respite care, which in the circumstances, may call for new approaches e.g. overnight stays within support bubbles or physically distanced day care in outdoor spaces such as public gardens.

Social isolation was a key feature of the negative impacts experienced during lockdown. It was experienced at different intensities and in different ways by different people, which is similar to findings in the baseline assessment of IDEAL (Victor et al., 2020). It always involved difficult feelings associated with being distanced from others, including loss of comforting physical contact; and being unable to meet and participate in supportive community life. Feeling low in mood, anxious or depressed were common accompaniments to social isolation (Clare et al., in press; Victor et al., 2020; Wu, Clare, & Matthews, 2019) and negatively impacted on coping during COVID-19 restrictions. Changes in level of coping between initial and follow-up interviews were often influenced by the extent to which participants were willing and able to take advantage of the lifting of lockdown measures to reduce their sense of social isolation.

Whilst there were many community initiatives aimed at combatting social isolation and associated feelings, the research identifies the support provided via 'just checking' services (Alzheimer's Society, 2020c) as particularly effective for all people living with dementia and their carers during this time. Such services were typically offered by voluntary organisations in the form of a telephone call that opened with a general enquiry as to the recipient's welfare and went on to discuss specific needs if necessary.

These telephone conversations were highly valued by IDEAL-CDI participants at the time of both initial and follow-up interviews, and appeared to be very effective in combatting any sense of abandonment they were feeling at each of those times. Given the relatively low cost, coupled with the actual and potential benefit demonstrated, there appears to be a case for maintaining and investing further in these types of services as we continue to live with the fact of coronavirus.

Social isolation was also combatted, in part, via continuation of existing services and meetings via online services and forums. The majority of people living with dementia in the IDEAL-CDI cohort benefited from the move online to a lesser or greater extent. However, a

small minority derived little or no benefit, either because they were disinclined to engage digitally or because they lacked the means and know-how to do so.

Even some of those who did derive significant benefit were feeling the limits of online engagement and there was an emerging perception of an over reliance of online services and forums that might draw attention away from the value of face-to-face services and meetings and eventually threaten their re-instatement. The policy and practice messages to be drawn from this are twofold. Firstly, efforts to ensure the digital inclusion of people living with dementia continue to be vitally important; secondly, a carefully considered balance of online and face-to-face services is required for the 'new normal'.

A further layer of protection against social isolation was provided by neighbourhood and community support services. Those in the 'coping well' group tended to draw on established networks of community support and to experience some element of reciprocity by contributing to the support of others. Those in the other two groups were more likely to draw on newly established forms of community support and to be recipients of assistance. Access to support from local groups and services has been identified as an important strategy to help tackle the effects of loneliness (HM Government, 2018).

The value of community support established during lockdown to provide assistance to those most vulnerable to the virus is not disputed in any way. However, it does appear that greater benefit may be derived from more inclusive forms of community support that enable people to simultaneously give and receive support according to their capacities and particular needs. This sets a challenge for community development initiatives in the emerging 'new normal' to operate on a principle of 'dementia inclusiveness'.

Dementia inclusiveness is premised upon dementia friendliness. The research identified a small number of incidents in which individuals supervising public spaces demonstrated a lack of dementia friendliness, but there were also many incidents of individuals acting in a dementia friendly way. Lockdown created an unfamiliar situation for everyone, but people living with dementia were particularly poorly placed to understand what was expected of them.

This was particularly so for people aged 75 or lower who were living with dementia; they expressed the greatest wish to emerge into public spaces as lockdown started to lift, coupled with the greatest anxiety about doing so. It was this fear that led many of this age group to be categorised as 'coping with some difficulty' rather than 'coping well'. This points to the continuing importance of dementia friendly communities as a construct for daily life and the need to further develop what it might mean in our new normal as we continue to live with coronavirus.

Fortunately, the evidence from the follow-up interviews gives cause for optimism in this respect. Some participants found that their willingness to explain something of their situation to people in a position to help them was well received and sometimes resulted in material changes that provided very practical assistance to them.

Finally, two individual accounts offer reminders in relation to some important policy and practice issues. The first reminds us that dementia does not exist in a bubble (Nelis et al., 2019) and other specialist services must be made accessible to people living with dementia and their carers e.g. domestic abuse services. The second reminds us that people who self-fund their social care can be less visible within the health and social care system (Henderson et al., 2019) and it is essential that we check that they have been able to establish adequate care and support arrangements as we emerge from lockdown and beyond.

Policy and Practice Suggestions

The policy and practice suggestions discussed are condensed into list form below with the aim of informing future discussion and co-production with a range of stakeholders:

Access to personalised health care:

- offering calls from a familiar primary care professional (not necessarily the GP) to discuss level of coping and personal health and care needs, if resources allow
- 'dementia awareness' training for health care staff to recognise differences and changes in coping during COVID-19
- improved links between dementia care and other local systems of formal and informal support
- promoting links between primary care and leaders of BAME community leaders to identify novel ways to engage with people from minority groups

Maintaining physical and mental well-being:

- maintain existing 'just checking' services and further develop capacity
- use existing sources of local knowledge to target checks for people living with dementia who live alone
- relaunch or refresh dementia friendly communities with local solutions to assist people with dementia to perform normal activities safely according to current COVID-19 restrictions

Support for carers:

- proactively contact individual carers to identify where carer support has stopped, offer proportionate assessments and respond to identified needs
- develop new forms of respite care to support carers such as overnight stays within support bubbles or physically distanced day care in public outdoor spaces

Information and support to all:

- promote digital inclusion of people with dementia and carers
- develop a blended approach to information and support for people with dementia during COVID-19 to include a variety of media such as online, print, TV, radio and face-to-face services
- ensure that information and support services are dementia friendly
- take into account different cultural needs and preferences for information and how it is delivered

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Authors:

Gareth O'Rourke^a, Claire Pentecost^a, Eleanor van den Heuvel^b, Christina Victor^b, Catherine Quinn^c, Alexandra Hillman^d, Rachael Litherland^e, Linda Clare^{a,f}

^a REACH: The Centre for Research in Ageing and Cognitive Health, College of Medicine and Health, University of Exeter, Exeter, UK

^b College of Health and Life Sciences, Brunel University London, London, UK

^c Centre of Applied Dementia Studies, University of Bradford, Bradford, UK

^d Department of Public Health Policy and Social Sciences, Swansea University, Swansea, UK

^e Innovations in Dementia CIC, UK

^f NIHR Applied Research Collaboration South-West Peninsula

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Appendix 1: Levels of coping

| Level of coping | Descriptors |
|---|---|
| Coping well with minor or no difficulties | <p>Lives with other (usually spouse) in a relationship that easily accommodates the needs of both.</p> <p>Limited sense of social isolation: i) use of existing systems of community support offer opportunities to support others; ii) online social support provides good compensation for lack of face-to-face contact.</p> <p>Lack of physical contact with family is tolerable (for now).</p> <p>Mild or moderately anxious to avoid catching the virus themselves or for family members to do so.</p> <p>Higher resilience and adaptability to the circumstances of lockdown (appears to mirror patterns of coping with earlier life challenges).</p> |
| Coping with some difficulties | <p>Lives alone or with a co-resident carer who is feeling increased stress as a result of their new caring situation.</p> <p>Moderate or high level of social isolation: i) use of newly established systems of community support is primarily as a recipient of services; ii) no access to online community support or only partial compensation from it for loss of face-to-face contact.</p> <p>Lack of physical contact with family is increasingly difficult.</p> <p>Moderate or higher level of anxiety is felt as a more immediate threat of catching the virus themselves.</p> <p>Anxiety about using public space. This anxiety is being projected forward to post lockdown arrangements.</p> <p>Resilience and adaptability is undermined by uncertainty about their ability to cope and what level of dementia friendliness to expect in the 'new normal'.</p> <p>Some loss of functional ability.</p> <p>Feeling low in mood or depressed.</p> |
| Just coping with significant difficulties | <p>Lives alone or with a co-resident carer in a relationship dominated by the needs of the person living with dementia; i) carers, both co-resident and visiting, have had to increase the range and intensity of coping tasks and are struggling to cope with their extended caring role; ii) pre-lockdown problems in the caring relationship have been exacerbated.</p> <p>Greater sense of social isolation is likely to be experienced as loneliness; community support is experienced as largely functional; no access to online community support or little or no compensation from it for loss of face-to-face contact.</p> <p>Lack of physical contact with family has become very difficult.</p> <p>Higher level of anxiety includes a fear of catching the virus and a more generalised, unspecified anxiety about the altered circumstances of lockdown.</p> <p>No garden or access to outside space.</p> <p>Some loss of functional ability.</p> <p>Feeling low in mood or depressed with greater difficulty understanding or retaining guidance on lockdown and social distancing measures.</p> |

Appendix 2: Interpretation of MMSE scores

| Score | Likely degree of cognitive impairment | Likely effect on daily functioning |
|---------|---|--|
| 25 - 30 | Very mild but questionably significant. | May have clinically significant but mild deficits. Likely to affect only the most demanding of activities of daily living. |
| 20 - 25 | Mild. | Significant effect. May require some supervision, support and assistance. |
| 10 - 20 | Moderate. | Clear impairment. May require 24 hour supervision. |
| 0 - 10 | Severe. | Marked impairment. Likely to require 24 hour supervision and assistance with ADL |

Adapted from: Folstein et al. (1975)

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