

Emotional and Mental Wellbeing Following COVID-19 Public Health Measures on People Living With Dementia and Carers

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Kerry Hanna, PhD BSc(Hons)^{1,*} ,
Clarissa Giebel, PhD MSc BSc(Hons)^{1,2,*}, Hilary Tetlow, MA³,
Kym Ward, MA⁴, Justine Shenton, MA BA⁵, Jacqueline Cannon, MBBS MRCPsych^{6,7},
Aravind Komuravelli, MBBS MRCPsych⁸, Anna Gaughan, MSc BA⁹,
Ruth Eley, MBA¹⁰, Carol Rogers, MBE¹¹,
Manoj Rajagopal, MRCPsych, MSc¹², Stan Limbert, MSc²,
Steve Callaghan, MSc¹³, Rosie Whittington, D.Clin.Psych, BSc¹⁴,
Sarah Butchard, D.Clin.Psych, BSc^{1,2}, Lisa Shaw, PhD, BA¹⁵, and
Mark Gabbay, MBChB, MD FRCGP^{1,2}

Abstract

Background: To date, there appears to be no evidence on the longer-term impacts caused by COVID-19 and its related public health restrictions on some of the most vulnerable in our societies. The aim of this research was to explore the change in impact of COVID-19 public health measures on the mental wellbeing of people living with dementia (PLWD) and unpaid carers. **Method:** Semi-structured, follow-up telephone interviews were conducted with PLWD and unpaid carers between June and July 2020. Participants were asked about their experiences of accessing social support services during the pandemic, and the impact of restrictions on their daily lives. **Results:** 20 interviews were conducted and thematically analyzed, which produced 3 primary themes concerning emotional responses and impact to mental health and wellbeing during the course of the pandemic: 1) Impact on mental health during lockdown, 2) Changes to mental health following easing of public health, and 3) The long-term effect of public health measures. **Conclusions:** The findings from this research shed light on the longer-term psychological impacts of the UK Government's public health measures on PLWD and their carers. The loss of social support

¹ Department of Primary Care & Mental Health, University of Liverpool, Liverpool, UK

² NIHR ARC NWC, Liverpool, UK

³ SURF Liverpool, Liverpool, UK

⁴ The Brain Charity, Liverpool, UK

⁵ Sefton Older People's Forum, Liverpool, UK

⁶ Wigan Dementia Action Alliance, Liverpool, UK

⁷ Lewy Body Society, Liverpool, UK

⁸ North West Boroughs NHS Trust, Warrington, UK

⁹ Together In Dementia Everyday (TIDE), Liverpool, UK

¹⁰ Liverpool Dementia Action Alliance, Liverpool, UK

¹¹ National Museums Liverpool, Liverpool, UK

¹² Lancashire and South Cumbria NHS Trust, Liverpool, UK

¹³ EQE Health, Liverpool, UK

¹⁴ Me2U Day Care Centre, Liverpool, UK

¹⁵ Department of Modern Languages and Cultures, University of Liverpool, Liverpool, UK

* Kerry Hanna and Clarissa Giebel are joint first authors.

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Corresponding Author:

Kerry Hanna, Department of Primary Care & Mental Health, University of Liverpool, Liverpool, UK.

Email: k.hanna2@liverpool.ac.uk

services was key in impacting this cohort mentally and emotionally, displaying a need for better psychological support, for both carers and PLWD.

Keywords

dementia, alzheimer's disease, anxiety, caregiver burden, elderly, health services research

Introduction

Dementia affects 50 million people worldwide,¹ and the psychological symptoms of dementia have been well established, including irritability, social isolation and depression.^{2,3} Irritability and social isolation often result in institutionalization and depression within older adults,⁴ causing further stress to the older adult and the unpaid carer.

Since January 2020, the COVID-19 pandemic has caused emergency closures and restrictions around the world, through which people from all backgrounds have reported psychological impacts.^{5,6} Such impacts are multifaceted; due to the virus itself and then exacerbated by the forced quarantine measure to tackle the spread of the virus, applied through national lockdowns.⁷ A recent review of the evidence describing the psychological impact of COVID-19 on the general population reported psychological manifestations to include acute panic, anxiety, obsessive behaviors, hoarding, paranoia, depression, and post-traumatic stress disorder.⁷

The UK Government imposed lockdown restrictions on March 23rd 2020, which stipulated severe restrictions on social contact, on the ability for many people to work, and greatly reduced access to services.⁸ High-risk groups including elderly people over the age of 70 were asked to remain at home and “shield,” further reducing social contact with family and friends.⁹ Although restrictions eased in June 2020, the UK has since experienced further regional lockdowns as a means to control the rise in COVID-19 cases.¹⁰ A longitudinal survey identified deterioration in mental health within the UK by April 2020 8, while a further large-scale panel study reported greater support needs for anxiety and depression in the UK since lockdown.¹¹

In the UK, dementia day centers and support groups were forced to close due to the pandemic.¹² The impact of national and regional restrictions as a result of the pandemic, including social distancing and shielding, has led to greater rates of social isolation, which further impacts those classed as most vulnerable in society, including people living with dementia (PLWD).^{13,14} Self-isolation will, therefore, disproportionately affect elderly individuals whose only social contact is outside of the home, such as at day-care venues and community centers.¹⁵

The aim of this research was to explore change in impact of COVID-19 public health measures since the time of first interview three months earlier, on the mental wellbeing of PLWD and unpaid carers. Evidence is emerging concerning the psychological impact of COVID-19 and its related public health restrictions on the general population. However, to date, there appears to be no evidence on the longer-term impacts on some

of the most vulnerable in our societies—those affected by dementia—as well as those caring for PLWD. It is important to understand the course of psychological impacts to better understand the need for social support.

Methods

A qualitative study design was adopted to explore personal experiences and generate data using in-depth, semi-structured interviews.¹⁶

Participants and Recruitment

PLWD with mental capacity, and unpaid carers, aged >18 years old, who were living in the community were eligible to take part. Unpaid carers who were currently caring for someone living with dementia, or who had previously cared for a PLWD but were still accessing social care/support services, were eligible to take part. Participants were recruited from various social support service and third sector organizations via convenience sampling and contacting people who were members of organizations individually. A sub-sample of the 50 participants originally interviewed for an earlier study¹² was randomly selected to have a mix of people living with dementia and carers in the follow-up interviews. The final sample consists of participants who underwent an earlier research interview and who were willing to partake in a follow up interview. A sample of at approximately half of the former were planned to identify change over time, with the expectation that some participants would not wish to undertake a further research interview. Ethical approval was granted by the University of Liverpool [ID 7626].

Data Collection

Telephone interviews were audio-recorded and transcribed, with verbal informed consent obtained prior to commencing the interview. Interviews were conducted by 2 authors (CG and KH) who are experienced qualitative researchers. A semi-structured interview guide guided the researchers to question participants' on their experiences in the months since the last interview, whether their situation had changed, whether support services had adapted, and whether they felt they received all the support they needed.

Data Analysis

Each transcript was double-coded manually, following the six-phase approach to descriptive, thematic analysis developed by

Table 1. Demographic Characteristics of Carers and People Living With Dementia.

	Carers (n = 16)	PLWD (n = 4)	Total sample (n = 20)
N(%)			
Gender			
Female	15 (93.8%)	1 (25%)	16 (80%)
Male	1 (6.3%)	4 (75%)	4 (20%)
Ethnicity			
White	13 (81.3%)	4 (100%)	17 (85%)
BAME	3 (18.3%)	0	3 (15%)
Relationship with PLWD			
Spouse	6 (37.5%)		
Adult child	10 (62.5%)		
Living with PLWD			
Yes	7 (43.5%)		
No	9 (56.3%)		
Dementia subtype			
Alzheimer's disease	8 (50%)	2 (50%)	10 (50%)
Mixed dementia	2 (12.5%)	0	2 (10%)
Vascular dementia	2 (12.5%)	1 (25%)	3 (15%)
Lewy Body dementia	0	1 (25%)	1 (5%)
YOD	3 (18.8%)	0 (0%)	3 (15%)
Other	1 (6.3%)	0	1 (5%)
IMD Quintile¹			
1 (least disadvantaged)	1 (6.3%)	0	1 (5.9%)
2	6 (37.5%)	0	6 (35.3%)
3	1 (6.3%)	0 (0%)	1 (5.9%)
4	2 (12.5%)	2 (50%)	4 (23.5%)
5 (most disadvantaged)	4 (25%)	1 (25%)	5 (29.4%)
Internet access			
Yes	15 (93.8%)	4 (100%)	19 (95%)
No	1 (6.3%)	0	1 (5%)
Mean (SD), [Range]			
Age	55.3 (± 6.2)[36–62]	66.5 (± 4.1)[61–71]	57 (± 7.4)[36–71]
Years of education	15.8 (± 3.4)[11–22]	14.3 (± 2.4)[11–16]	15.5 (± 3.2)[11–22]
Years since dementia diagnosis			4.5 (± 2.6) [0.5–9]
Weekly hours of social support service use before COVID-19			12.5 (± 13.6)[0–52]
Weekly hours of social support service use since COVID-19			5.4 (± 11.5) [0–44.5]

¹missing data for 2 carers and one PLWD (IMD).

Braun and Clarke.¹⁷ Thematic analysis was chosen as a flexible approach to identify and organize themes and produce meaning from the data.¹⁷ Following coding, the research team met to discuss the codes, generating initial themes inductively, which were then reviewed and defined collectively. All members of the research team agreed the three final themes. Descriptive statistics, using means/SD for the continuous data, were used to summarize the participant demographics.

Public Involvement

The research team consisted of researchers, clinicians (GP, psychologists, psychiatrists), third sector care providers, and further included public involvement from 1 PLWD and three former unpaid carers to ensure interpretation and implications of findings were grounded within the lived experiences of those

affected by dementia. Their roles involved conceptualizing the study, designing the interview guide, interpreting the findings and supporting dissemination.

Results

Demographics

Fifteen unpaid carers, one former carer and 4 PLWD (ntotal = 20) took part in the follow-up interviews. Participant demographics are shown in Table 1. The majority were female (80%) and aged 57 ± 7.4 years. Carers were frequently the child of the PLWD (62.5%) and lived in a separate home (56.3%). Two PLWD resided in a care home pre-COVID, and a further 2 since COVID-19. Dementia subtype varied from Alzheimer's disease (n = 10, 50%) to vascular (n = 3, 15%) and Lewy body dementia

Table 2. Coding Tree Following Thematic Analysis.

Themes	Subthemes
1) Impact on mental health during lockdown	Loneliness Carer anxiety Depression/increased medication use
2) Changes to mental health following easing of public health measures	Relief Stigma and shaming when re-entering society Living in fear of the virus
3) Long-term effect of public health measures	Irreversible increase in carer burden Ongoing stress /uncertainty, and loss of hope

($n = 1, 5\%$), with three (15%) reporting young-onset dementia without a specific dementia subtype.

IMD quintiles showed that carers lived in a mix of disadvantaged and more affluent neighborhoods, but PLWD tended to live in more disadvantaged neighborhoods.

Thematic Analysis

Following analysis, three main themes developed that centered on the emotional and mental welling of the PLWD and carers during the time of COVID-19. These themes described the trajectory of the participants' emotions, which evolved and changed throughout the course of the pandemic: 1) Impact on mental health during lockdown, 2) Changes to mental health following easing of public health, and 3) the Long-term effect of public health measures. Table 2 shows the coding tree inclusive of subthemes.

Theme 1: Impact on Mental Health During Lockdown

Loneliness

Loneliness was described by PLWD during lockdown due to the loss of social contact, through the closure of support services and compliance with shielding and public health restrictions. However, poignant accounts further described the loss of friends to care homes during the time of the pandemic, as their dementia symptoms worsened.

“we get a lot of support from the professionals at [Hospital] for a start. I feel as though we're three quarters of the way there but I'd like to be visiting friends that unfortunately have ended up in nursing homes now that I've been associated with for the last 7 years, but unfortunately have gone into institutional care. We can't do that sort of thing and I miss those people” Male PLWD (living alone), ID 8

Carers also expressed their loneliness during the period of lockdown. Often this was attributed to their main social contact being the PLWD, for whom they cared for. This proved increasingly difficult as social interaction was limited following the decline in cognition and memory. Furthermore, carers

felt isolated as friends and family members, who previously supported them, were now also in lockdown and unable to help.

“it has been hard because we [carers] just haven't obviously had that support. You can't ask family for any support really because everyone's in lockdown . . . it's been really, really like it has been stressful at times” Female carer (daughter), ID 14

Carer Anxiety

Many carers specifically noted new counts of anxiety and stress which they attributed to the noticeable deterioration in emotional wellbeing observed in the PLWD. They felt under pressure to provide the much-needed additional support and stimuli following the loss of dementia day care centers and paid care support, for example, and were distressed in observing the rapid decline in the PLWD.

“I also contacted the social worker to ask for further help because I felt the situation at home was becoming more difficult . . . I just felt my mum's condition was worsening in terms of like metal state and also her mobility . . . she was doing quite a lot of screaming when she was going to the toilet or when she was having to do anything.” Male carer (son), ID 5

Depression and Increased use of Medication

Both PLWD and carers, reported depressive symptoms during lockdown, and the new use of medication prescriptions to tackle the mental health and health issues resulting from this. Participants reported that isolation, the loss of social interaction, and increased stress resulted in feelings of depression.

“the psychiatrist, they gave me some antidepressants . . . I didn't want to take it but I felt as though I was going downhill a little bit, it's that I felt so isolated is the better way of putting it, I wasn't seeing another human face at all, no direct contact with anybody, not even a window cleaner. Crazy I know, everything stopped instantly it was like turning the light off it was that quick wasn't it when you think about it” Male PLWD (living alone), ID 8

Theme 2: Changes to Mental Health Following Easing of Public Health Measures

Relief

Immediately following the easing of some public health measures in July 2020, participants described a sense of relief and freedom as they could now leave their homes and see other friends and family members.

“I was shielding . . . for 12 weeks but they changed the criteria which meant that I could go out you know after 6 weeks . . . it just gave me that, I've lost my sense of freedom, I mean I don't go out much anyway but there's a difference in . . . choosing not to go out as opposed to, it's similar to house arrest” Male PLWD (lives with wife), ID 11

Over time, many adapted to the public health restrictions and guidance, and were able to increase their paid care support. A further sense of relief was described as the additional care support relinquished some of the stress and burden the carer was experiencing.

“well I think it’s invaluable I couldn’t have done it without them [paid carers] to be honest that’s why the care package had to change because I couldn’t carry on without extra care . . . at the beginning of when we first went into lockdown I was quite concerned about people coming back into the house but I think it’s a case of, well if I ended up doing this on my own for 3 months, there’s no way I could have done that on my own” Male carer (son), ID 5

Stigma and Shaming When Re-Entering Society

Few carers went out with PLWD during the time of the lockdown/public health measures, as many shielded at home. Those that did however, described negative experiences where the PLWD did not fully understand the measures, increasing carer stress. Feelings of embarrassment were described when shopping with the PLWD who struggled to adhere to the new measures.

“she [PLWD] said she wanted to go to this supermarket that she like . . . she kept wanting to push closer to the lady in front . . . I said no mum you can’t do that you have to stay 2 meters behind the person in front of you . . . I said and you need to follow the arrows round the supermarket” Female carer (daughter), ID 30

Societal shaming was further portrayed due to the stigma of breaching public health guidance, such as coughing, and the inability to use a facemask or socially distance. This finding highlights a lack of understanding and acceptance from the general public, and a need to raise awareness of the capabilities and challenges facing carers and PLWD when entering society under the new restrictions.

“my dad has a machine to help his breathing, he should be using it if he remembers . . . But it makes him belch a lot . . . so if he’s out and about and belching . . . you can understand how people around him might look at him. But it’s also a case of him wearing a mask which is mandatory or supposed to be mandatory from today onwards . . . we’re getting cards . . . to say that he has a disability, but it’s also a case of some people still won’t understand that, so I’m anxious as to how that’s going to go” Female carer (spouse) ID04

Living in Fear of the Virus

Despite the easing of public health measures, carers and PLWD remained fearful of catching and spreading COVID-19, which affected their mental state. Overall, it seemed PLWD and carers took a cautious and apprehensive approach to re-entering society, and felt, somewhat disappointingly, that life was not as it was before COVID-19.

“in many ways the bigger risk to us is if I catch COVID because if I got it bad there would be nobody to look after [PLWD]” Female carer (spouse), ID 31

“it was just dropping off a cliff . . . mum’s care home has 42 residents, I believe 8 died [from COVID19] so we’re looking at 20% . . . it has been catastrophic” Female carer (daughter) ID 35

Fears of virus transmission were intensified when others failed to adhere to public health measures and hygiene rules. Where carers witnessed breaches in hygiene control from paid carers in the home, or from reports of rule breaking in the media, participants reported feelings of increased stress and frustration, as they felt they were being put at risk.

“even though I have set carers . . . it’s been a very mixed experience . . . because some people haven’t quite grasped the idea of what shielding is about and why you know why as carers you should be following you know the guidelines and you know forgetting to wash your hands, putting you gloves and simple things . . .” Female carer (spouse), ID 36

Regret

Earlier decisions made in the initial stages of lockdown to protect the PLWD included canceling paid care, shielding with the PLWD in their home, or placing the PLWD in a care home despite the reportedly high rates of COVID-19 in care homes at that time.¹⁸

“I’ve had no breaks at all whatsoever in this but that has been by choice, I wouldn’t want a carer coming in here unnecessarily because A; I couldn’t go out anywhere anyway could I where could I go except walk round and round outside on my own and B; I wouldn’t want the germs coming in on a on a carer either, well I made that decision to suspend my carer breaks” Female carer (spouse), ID 22

However, while reflecting on their earlier decisions, carers battled feelings of guilt and regret. Feelings of guilt stemmed from not making decisions sooner, which ultimately led to improve their situation. While others described regretting earlier decisions, such as canceling care, due to the impact this had on their mental wellbeing through increased burden.

“I actually went and stayed with them 24 hours a day erm so that I could keep [PLWD] active and away from [PLWD’s husband] so he could rest . . . Oh God the more I’m talking the more I think I’m just terrible I should have done that more often” Female carer (daughter-in-law), ID 42

Theme 3: The Long-Term Effect of Public Health Measures

An Irreversible Increase in Carer Burden

Following the decision made by carers to shield with the PLWD, or to cancel paid care and take on the additional caring duties in a bid to minimize risk, a greater level of reliance and

dependency was noted as the PLWD was doing less independent tasks, such as shopping and socializing. This decline in independence furthered feelings of carer stress.

'he's needed much more care and that has had the knock-on effect of course because the level of care is more intense in a way. I needed more, even if brief, even if it was an hour to go and do something different, I needed slightly more breaks but of course I couldn't get them at all and so I have found I've been getting quite yes quite anxious, stressed a bit stressed.' Female carer (spouse), ID31

However, many carers expressed a fear that this increased burden will remain long after COVID-19 has passed. This was due to a suspected, permanent decline in the health and independence of the PLWD, and the expected reliance on the carer to undertake activities which were previously carried out by the PLWD before the time of COVID-19.

"I started, just before lockdown started, I do a big shop for them once a week and then deliver the papers to them every day and you know pick up bits for them that way...I think they've become really reliant on it and I can't see it ever stopping...I don't think they'll do a weekly shop again" Female carer (daughter-in-law), ID 42

Ongoing Stress and Uncertainty, and Loss of Hope

Despite the easing of public health restrictions, participants did not necessarily feel positive for the future, with many describing ongoing anxiety due to feelings of uncertainty. A common reason for ongoing stress and worry related to the persistent closure of dementia support services, with no indication of reopening, and thus no sign of respite for the carer and much needed socialization for the PLWD.

"I'm in a situation where I've got no indication when the day centres are open, I can't seem to get regular sit-ins, I can't get her [PLWD] in the car so it's been quite difficult really. I think coming out of this has proven quite difficult...nationally there's a sort of sense of it easing but I think for someone like myself or other carers I imagine that easing is not really very straightforward and it could be a while before things, they ever get back to normal you know" Male carer (son), ID 5

Furthermore, with subsequent local lockdowns witnessed in certain regions of the county, participants expressed a 'loss of hope', as an easing of restrictions suddenly appeared inconsistent and transient.

"we have no control over it [lockdown], that's one thing and there seems to be no end to it, when we thought there was an end like I say when we had that little bit of hope that lockdown was easing then [area name] was put back into lockdown...we don't know when that's going to end and then will it actually end or will they continue it..." Female carer (daughter), ID 38

Similarly, participants spoke of the initial stages of lockdown more positively, harboring a belief that restrictions would be short lived. Over time, participants reported a growing concern and began to lose hope and optimism."

"it does feel like it's been getting a bit harder. To start with we had lots of jobs that we hadn't got done because we were always busy doing activities... Then over time I think the lack of activity might have increased [PLWD]'s deterioration, the progress of his dementia, so he's needed much more care and that has had the knock-on effect of course because the level of care is more intense in a way, I needed more, even if it was an hour, to go and do something different...but of course I couldn't...and so I have found [that] I've been getting quite yes quite anxious, stressed, a bit stressed" Female carer (spouse), ID 31

This finding highlighted that, without clear guidance and support, PLWD and carers will be unable to cope well with the ongoing concern and burden of the public health restrictions.

Discussion

This research follows on from earlier reports of deterioration in dementia symptoms following the closure of social support services due to COVID-19,¹² and adds to the emerging evidence base by reporting the trajectory of emotional impact of COVID-19 public health measures on the mental health and wellbeing of PLWD and unpaid carers. The findings highlight the participants' emotional responses following the various changes in public health restrictions, with similarities and differences noted in the experiences of PLWD and carers.

Alongside changing restrictions across the UK, participants experienced changing emotional states. Participants described initial feelings of stress and anxiety when entering lockdown, predominantly as support services could not be accessed. This notion is supported by recent evidence, stating that the general UK adult population scored poorly on a range of mental health questionnaires taken during the initial period of lockdown in the UK.¹⁹ However, greater impact has been noted in older adults, and vulnerable groups due to the extreme shielding measures, comorbidities, and limited access to internet and smartphones to improve communication,^{20,21} which applies to many of the current study participants. Overall, these collective findings suggest an unmet need in social care support during the initial stages of lockdown, while the current research findings shed light on the specific impact this loss of support placed on the mental wellbeing of PLWD, and consequently, unpaid carers.

The sudden loss of day care centers and support groups, among others, resulted in feelings of loneliness, anxiety, and depression in PLWD and carers. The inability to access dementia services during the pandemic has been noted in earlier research where reductions in social support services were linked to anxiety in PLWD.^{12,22} This finding elucidates the benefits that support services bring to the lives of PLWD, but also to carers, and concurs with previous evidence reporting

links between loss of socialization and depression in dementia.^{2,4}

Loneliness has been reported in older adults during the time of COVID-19, with higher rates found in those with medical conditions, fewer face-to-face interactions and an absence of regular activities,²³ which resonates with PLWD. Generally, loneliness has been linked to morbidity in older adults,^{24,25} and has also been linked to exacerbated clinical signs of dementia.²⁶ In our study, isolation and loneliness were further experienced by the PLWD following the sudden loss of social support, routine, and the lack of subsequent guidance in navigating the new, post-lockdown measures. Moreover, carers described feelings of stress in trying to support the PLWD under these new restrictions, while those that opted to shield with the PLWD described additional feelings of loneliness. These findings add to the developing evidence base while further providing new insight to the specific impact the pandemic is having on the mental health and wellbeing of PLWD and unpaid carers

There appears to be a clear need for psychological support, for both carers and PLWD during the time of COVID-19, signposting alternative means of support besides the medication prescriptions described by the participants. Many carers are burdened by caring for a relative with dementia outside of the scope of the pandemic,²⁷⁻²⁹ with the pandemic having heightened levels of burden on many, as our study shows. Recommendations have been suggested to support the mental wellbeing of PLWD during the time of the pandemic, including urgent psychological and mental health support, guidance on appropriate relaxation practices reduce stress, and for families to share the caring role for a relative with dementia in instances where social care has been lost.³⁰ Participants from our research expressed a desire to recommence support group meetings and activities safely, where possible. Suggestions have been postulated to allow safe, social contact, including “cuddle curtains”^{31,32} and access to green, open spaces.^{33,34} However, such suggestions have yet to be formally explored and implemented, suggesting an area for future research and policy. Thus, providers should be encouraged to actively co-design means of safely encouraging social interaction during the time of the pandemic, to reduce loneliness and avoid the wider negative implications for mental health.

Our study benefits from interviewing PLWD and carers early on in the pandemic and including both perspectives, however there are some limitations to consider as part of our research. Although the purpose of qualitative research is not to generalize findings to wider cohorts, it should be noted that few people from BAME background undertook this research due to the convenience sampling method. In addition, a smaller number of PLWD participated compared to unpaid carers, and so their views may be less represented. However, the sample represents similar numbers recruited to the initial interviews for representative comparisons. Furthermore, PLWD are often excluded from research due to mental capacity, therefore a small sample still provides some representation that may otherwise be missed.

The study may be limited as interviews could not be conducted face-to-face, however the research team were experienced qualitative researchers and did not observe any issues during the interview process.

Conclusions

Public health measures, including social isolation and closure of support services, have had a severe impact on the mental and emotional wellbeing of the PLWD and unpaid carers in this study. However, little/no psychological support appears to have been made available, and a strong need for access to support services has been identified. As negative impacts to mental health can have far-reaching implications in vulnerable, older groups, it is imperative that psychological support is offered to both PLWD and unpaid carers during the time of COVID-19, and beyond. The sense of uncertainty with the possibility of future restrictions will continue to impact mental health and emotional wellbeing within this cohort, and therefore both groups will remain at risk of the wider implications of such impacts to mental health until sufficient support is made available. Our findings suggest providers need to be more imaginative, flexible, and resourceful on how to provide support that keeps transmission risk low during pandemics, while also supporting the needs of their clients and unpaid carers.

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ORCID iD

Kerry Hanna  <https://orcid.org/0000-0001-7357-7749>

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