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Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study

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ABSTRACT

Objectives: Accessing social care and social support services is key to support the well-being of people living with dementia (PLWD) and unpaid carers. COVID-19 has caused sudden closures or radical modifications of these services, and is resulting in prolonged self-isolation. The aim of this study was to explore the effects of COVID-19 related social care and support service changes and closures on the lives of PLWD and unpaid carers.

Method: PLWD and unpaid carers were interviewed via telephone in April 2020. Transcripts were analysed using thematic analysis. Demographic characteristics including household Index of Multiple Deprivation score and weekly hours of social support service usage before and since the COVID-19 outbreak were also collected. Paired samples t-tests was used to compare the mean of weekly hours of social support service usage before and since the outbreak.

Results: 50 semi-structured interviews were conducted with unpaid carers ($n=42$) and PLWD ($n=8$). There was a significant reduction in social support service usage since the outbreak. Thematic analysis identified three overarching themes: (1) Loss of control; (2) Uncertainty; (3) Adapting and having to adapt to the new normal. Carers and PLWD were greatly affected by the sudden removal of social support services, and concerned about when services would re-open. Carers were worried about whether the person they cared for would still be able to re-join social support services.

Conclusions: PLWD and carers need to receive specific practical and psychological support during the pandemic to support their well-being, which is severely affected by public health restrictions.

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KEYWORDS

Dementia and cognitive disorders; quality of life/wellbeing; social support; COVID19

Background

On New Year's Eve 2019, China announced the first case of the novel Coronavirus (COVID-19). Since then, strict public health measures have been implemented across the globe, affecting face-to-face meetings and care provision. With an estimated 50 million people living with dementia worldwide (ADI, 2016), the virus outbreak and associated public health measures are also likely to have significant negative impacts on the lives of those living with dementia, as well as those caring for them. In the UK alone, by 2025 over 1 million people are estimated to be living with dementia (Alzheimer's Society, 2014). Although unpaid carers form the largest part of the dementia care workforce in the UK (Alzheimer's Society, 2014), not all care should or can be provided by unpaid carers though. Consequently, access to social support services and paid carers are essential for both the person living with dementia (PLWD) and their unpaid carer. This is particularly crucial as COVID-19 is linked to increased deaths in PLWD (ONS, 2020), resulting

in 10,000 extra deaths in England and Wales since the pandemic as of June.

The social care sector in the UK has been in a crisis even before the pandemic. Once people receive a diagnosis with dementia, they are left to be supported by the social care sector, which includes paid home care and care homes, as well as other forms of socially based support which are not clinical as such. These can be privately or governmentally funded, and it depends on someone's income if they receive financial support from the government to access specific social care services. As part of this, social support services, including support groups, social activities such as singing and dancing groups, day-care centres, befriending services, respite, meal deliveries, can also be accessed after a dementia diagnosis, with services often provided by third sector organisations, and services available to both the PLWD and the carer. Whilst social care is means-tested, we refer to these various types of services as social support services for dementia, as they all, ranging from day care centres to peer support groups, provide some form of social support.

Accessing social support services such as support groups are vital to staying socially engaged, which in return is linked to improved levels of well-being (Giebel, Challis, & Montaldi, 2016). Equally, accessing support as an unpaid carer is vital to remain at a good level of well-being and reduce carer burden (Vandepitte et al., 2016). However, not everyone accesses the same level of post-diagnostic support with people experiencing inequalities in access (i.e. Cooper et al., 2016; Stevnsborg, Jensen-Dahm, Nielsen, Gasse, & Waldemar, 2016). This may have been further exacerbated by COVID-19 related public health restrictions, although no evidence has been gathered on this to date.

As a result of the COVID-19 pandemic, and the virus' potentially lethal outcome particularly among more elderly and those with chronic conditions or lowered immunity, populations in almost every nation have been placed on 'lockdown' to avoid the spread of the virus. The Coronavirus causes worse symptoms and outcomes among older people and those with pre-existing conditions (Jordan & Adap, 2020), so that older people in the UK particularly have been placed on an extended self-isolation period. Being unable to go out or see family and friends however can place a significant strain on people's well-being. This 'lockdown' also results in social support services being closed down, severely restricted or reformulated. For people living with dementia and unpaid carers this can have a particularly detrimental impact, with closures of support groups, social activities, respite care, and day care centres for example generally providing vital social and emotional support, where people are able to access these (Camic, Hulbert, & Kimmel, 2019; Mittelman & Papayannopoulou, 2018; O'Connell et al., 2012; Rokstad et al., 2017). Unpaid carers need these 'time outs', to not only reduce potentially becoming over-burdened with caring for someone with dementia, but also to receive peer support from peer carers by accessing support groups (Lauritzen, Bjerrum, Pedersen, & Sorensen, 2019). Engaging in peer support groups, social activities in the communities, or day care centres does equally have a positive impact on PLWD's well-being (Camic et al., 2019; Rokstad et al., 2017).

Moreover, paid home carers also form a vital part of dementia home care for the PLWD, which may equally be affected by COVID-19. Home care services often involve various different care workers visiting the person's home within a day or week. Paid carers now need to adapt by using personal protection equipment (PPE, such as disposable gloves, aprons, mouth and eye protection), whilst the social distancing aspect can be difficult to maintain if a PLWD requires personal care such as washing or getting dressed. Without any research conducted to date, yet only an editorial highlighting the potential impacts of COVID-19 on dementia care (Wang et al., 2020), it is unclear how the virus outbreak has affected this and other important social support and care services in dementia.

The aim of our study was to explore the effects of COVID-19 related social care and social support service closures on the lives of PLWD and unpaid carers. In this unprecedented time, to date, limited research has explored the effects of a pandemic-related, particularly COVID-19 related, social care and social support service closures on the lives of PLWD and unpaid carers. Given the need for

adequate social care and social support services in dementia to support PLWD and unpaid carers live well, service closures without adaptations to remote service provision are likely to have a negative effect on the lives of PLWD and unpaid carers. Atchinson, Bowman, and Vrinten (2020) already reported on the first socio-economic variations in relation to COVID-19. Our study provides crucial insights specifically for the social care sector and dementia services into the service reduction of psychosocial impacts of COVID-19 upon vulnerable populations.

Methods

Participants and recruitment

Unpaid carers who were caring for someone living with dementia at the time of the study or who have cared for a PLWD in the past, but where still accessing social care or social support services were eligible to take part. Unpaid carers had to be aged 18 or over. PLWD with mental capacity were also eligible to take part. Social care and social support services included for example day care centres, respite care, peer support groups, befriending services, publicly or privately funded home care, or meal deliveries.

We recruited participants via convenience sampling via social care and social support services predominantly across the North West Coast of England, but also nationally via dementia support organisations. For this purpose, services provided information about the study in regular newsletters, social media channels, and directly contacted eligible participants over the telephone and discuss the study. Contact details of interested unpaid carers and PLWD were forwarded to a researcher, who then contacted the participants. Because of the urgency of conducting the research and importance of gathering data quickly within the early time frame of the pandemic, the groups of PLWD and carers were filled from the list of participants who were interested in taking part in order of having contacted us. We did focus on getting more PLWD involved. However, this was difficult as more carers approached us to participate and we needed to have a time cut off of 4 weeks so as to capture a specific point in time without changes to the lockdown situation or other services.

We obtained ethical approval through the University of Liverpool [ID 7626].

Data collection

We undertook telephone interviews during April 2020, which lasted up to 50 min, and were audio-recorded. At the beginning of the interview, the researcher took verbal informed consent, which was also audio-recorded. Interviews were conducted by CG and DCLinPsych trainees, all of whom were experienced in conducting qualitative research. The semi-structured interviews were conducted using a topic guide, containing questions about the participant's service use before and after the Covid-19 outbreak and governmental restrictions.

We also collected background data on participant age, gender, ethnic background, postcode (to generate an Index of Multiple Deprivation), whether participants were living with the person with dementia (if carer) or living situation

(alone/with someone) (if PLWD), type of dementia, time since diagnosis, as well as weekly hours of informal care provided before and after COVID-19 and weekly hours of accessing social support before and after COVID-19.

Our topic guide was co-produced between the academic team, practitioners, PLWD and carers, focusing on experiences before and after the COVID-19 pandemic in respect of care services, coping, symptoms, challenges, benefits, strategies and impacts.

Data analysis

Audio recordings were transcribed into verbatim scripts by a paid University typist with extensive transcribing experience. Each transcript was anonymised and re-read for accuracy, allowing the authors to fully immerse themselves in the narratives before coding. Data were analysed using both inductive and deductive thematic analysis (Braun and Clarke, 2006) by eight research team members (CG, MG, SB, LS, JC, SC, KH, KW) and trainee clinical psychologists, to understand the impacts of public health restrictions on the lives of those living with dementia and those caring for someone with dementia. Line-by-line, manual coding of each transcript was employed individually by two researchers/trainees, and identified codes were discussed jointly to generate themes. Up to 35 transcripts were coded using inductive thematic analysis, which were discussed between transcribers. This generated the identified themes, with subsequent transcripts being coded using deductive thematic analysis to complement those themes.

Public involvement

One PLWD and three (former) unpaid carers formed part of the research team, and assisted with conceptualising the study, designing the interview guide, interpreting the findings and with dissemination. This ensured that the study and the interpretation and implications of findings were grounded in the lived experiences of those affected by dementia.

Results

Participant demographics

We completed 50 semi-structured interviews with unpaid carers ($n=42$) and PLWD ($n=8$). Most participants were female (76%), with most carers being spouses (55%). The majority of carers were living with the PLWD, with five carers where the PLWD resided in a care home. The types of dementia varied from Alzheimer's disease dementia (43%) to Lewy body dementia (6%) and vascular dementia (16%), with 12% of unpaid carers caring for/PLWD living with young-onset dementia without a specific dementia subtype. Carers lived in a mix of disadvantaged and more affluent neighbourhoods, based on their IMD Quintile, with PLWD tending to live in more disadvantaged neighbourhoods. Participant demographics are summarised in Table 1.

Themes

Thematic analysis resulted in three over-arching themes with various sub-themes about how COVID-19 related public health measures have affected the lives of those living with or caring for someone with dementia: (1) Loss of control; (2) Uncertainty; (3) Adapting and having to adapt to the new normal.

Theme 1: loss of control

Many carers and PLWD experienced a loss of control over the situation, with drastic changes having taken place when lockdown commenced. This appeared to have had an impact on increased symptom deterioration.

Drastic changes due to coronavirus outbreak

Participants highlighted the quick and drastic changes that took place as a result of public health measures due to the pandemic, with many PLWD and carers having previously enjoyed and accessed either a small or large number of varied social support activities. These have had to come to a halt suddenly.

"obviously with the Coronavirus things have changed quite drastically for us. Up until then Mum was having 6 carers a day, 2 in the morning, 2 at round about teatime and then 2 at night to help her to bed and she accessed respite herself at a day centre which she loved going to every Thursday. On a Monday she would go to a local café where there's a little group was set up by some carers that worked for the Council and on a Wednesday she was going to our singing group which I founded about 8 years ago called singing for fun."

Female Carer, Interview 21

"takes half an hour to get there so we've got the anticipation and we get in the car and we drive to wherever we're going and then we have our session and then we drive back and then we you know we debrief as we drive back and then I settle them back in the flat and we talk about the session and it's a real stimulus. For me now all of that is we have no release from the 4 walls I mean of the flat and trying to find ways of externalising you know and engaging [PLWD] with the world around her but she cannot physically be there and that is very hard."

Female Carer, Interview 42

Faster deterioration. Many carers were concerned about faster deterioration of the dementia symptoms as a result of COVID-19 public health measures. Specifically, with PLWD now unable to go through their daily routines by attending social activities or visiting support groups, PLWD appeared to lack the mental stimulation. This left many carers stating that their relatives/people they cared for had progressed much faster since the lockdown.

"I think that the longer this goes on the more he won't be able to go back to the things that he was doing. He would go into the village himself and go to get a few bits of shopping sometimes or he would walk up to church. That's another thing because church has stopped, he used to go up to church and he'd go and see my mums grave and all of that's stopped as well."

Female carer (Daughter), Interview 44

Being physically restricted to the house and unable to engage in previously enjoyed social activities, such as walking

Table 1. Demographic characteristics of people living with dementia and carers.

	Carers (n = 42)	PLWD (n = 8)	Total sample (n = 50)
N(%)			
Gender			
Female	35 (83.3%)	3 (37.5%)	38 (76%)
Male	7 (16.7%)	5 (62.5%)	12 (24%)
Ethnicity			
White	39 (92.9%)	8 (100%)	47 (94%)
BAME	3 (7.1%)	0	3 (6%)
Relationship with PLWD			
Spouse	23 (54.8%)		
Adult child	19 (45.2%)		
Living with PLWD			
Yes	23 (56.1%)		
No	18 (43.6%)		
Dementia subtype			
Alzheimer's disease	19 (46.3%)	2 (25%)	21 (42.9%)
Mixed dementia	4 (9.8%)	0	4 (8.2%)
Vascular dementia	5 (12.2%)	3 (37.5%)	8 (16.3%)
Lewy Body dementia	2 (4.9%)	1 (12.5%)	3 (6.1%)
YOD	4 (9.8%)	2 (25%)	6 (12.2%)
Other	7 (17.0%)	0	7 (14.2%)
IMD Quintile			
1 (least disadvantaged)	5 (13.2%)	0	5 (11.1%)
2	14 (36.8%)	0	14 (31.1%)
3	8 (21.1%)	1 (14.3%)	9 (20%)
4	4 (10.5%)	3 (42.9%)	7 (15.6%)
5 (most disadvantaged)	7 (18.4%)	3 (42.9%)	10 (22.2%)
Mean (SD), [Range]			
Age	60 (+/-8.8) [36-74]	63.6 (+/-6.5) [50-71]	60 (+/-9) [36-74]
Years of education	15.9 (+/-3.8) [11-26]	13.5 (+/-2.6) [11-17]	15.5 (+/- 3.7) [11-26]
Years since dementia diagnosis			5.1 (+/-3.4) [0.1-15]
Weekly hours of social support service use before COVID-19			12 (+/-12.9) [0-52]
Weekly hours of social support service use since COVID-19			4.5 (+/-8.9) [0-44.5]

¹One carer was a former carer, and thus was not classed as either living or not living with the PLWD.

or dancing groups, or going to a bar with a befriender, have had an effect on the PLWD's physical well-being. People were less likely to engage in any form of physical activity and some showed symptoms of physical deterioration. This was particularly pronounced for PLWD who were physically fit and active pre-pandemic, many of whom were younger, with sudden restrictions not only affecting their physical health but also their general well-being.

"Five weeks ago my Dad was a totally different person than he is now and he won't come back from this."

Female carer (Daughter), Interview 38

"we also really enjoyed the dementia friendly sessions at the local swimming pool and went there every week and Ken had a group of friends who I introduced him to via a friend of mine who are all retired unlike Ken, they took him his wing and they used to go for lunch once a week at Wetherspoons and just chitchat about that. [...] So he had a really quite an active social life really and I spent a lot of time just organising things so some of the, there was a lot that he could do. [...] finding him things to do at the moment is a challenge"

Female carer (Spouse) to PLWD with young-onset dementia, Interview 13

Handling care and paid carers

Some carers experienced a loss of control surrounding managing the PLWD's care. Considering the vast number of different paid carers usually entering a PLWD's home, many carers who continued having paid carers visit their PLWD expressed concern over where carers had been previously, and the lack of control over who comes in to visit the PLWD. Paid carers might bring in the virus, yet unpaid carers were often reliant on continued care support as they were unable to cope otherwise, or would lose their

financial support for paid care and would face significant barriers when re-applying for a care package.

"My daughter's finished school now, she's 16, so we were able to manage mum's care and it was quite a relief that we wasn't having people coming in or whoever and it was stopping cross contamination coming in, it was just us erm but I phoned up to see what our rights were because of the COVID and I was told that anything over 14 days stopping we lose the package and we have to go back to social services and if we get a package again so the anxiety in that is massive."

Female carer (daughter), Interview 14

Theme 2: uncertainty

What will happen afterwards?

There was a general concern and worry about the uncertainty of the re-opening of social support service provision in the future and how this would be achieved. As part of this, carers felt concerned over whether their PLWD would still be able to access previously enjoyed services and activities if they had been unable to access them and see their peers for a substantial period of time. This has caused PLWD to forget their peers in many cases, and PLWD might be too advanced in their dementia, also due to a lack of mental and physical stimulation as a result of COVID-19 public health restrictions, to access these activities in the future.

"she has basically forgotten the people that she saw in her social care groups. She really only remembered them each week that she saw them because she's not seen them for long enough for them to register in her long-term memory"

Female Carer, Interview 42

"I think we would were having a conversation, myself and some of the volunteers who run the singing groups wondering when we do return what impact that amount of time has had for the

people, well for of us actually but in particular the people living with dementia on memories on the songs that we have we have learnt and you know it will be an interesting time."

Female Carer, Interview 21

"I'm just hoping all these services eventually do come back and they come back sooner rather than later because then and my Dad hasn't been out, he hasn't been the shops he hasn't been obviously walking and he really him and my Mum loved to go for coffees we used to go like the garden centre if it was nice and he really likes that because he really loves being round people."

Female carer (Daughter), Interview 24

Uncertainty about public health restrictions

Many PLWD were struggling to understand the new public health restrictions, resulting in unpaid carers repeatedly trying to explain why people are supposed to stay indoors or are not supposed to come within less than a two-metre radius of someone. Thus, many PLWD who were likely to have been in the more advanced stages of the condition did not comprehend why their support groups, day care centres, or befriending services were currently not taking place. This also resulted in some PLWD not being allowed out of the house for a walk on their own, as they would otherwise forget about the public health measures and approach strangers or friends, which can cause strain on the relationship between carers and PLWD with carers having to pose restrictions on the PLWD's life.

"I'm having to get close to her whilst showering her and I'm very conscious of that all the time I'm bringing her nearer, I hope I'm not passing anything on and there's been a couple of occasions where when I've gone to help Mum she's then just grabbed hold of me and hugged me."

Female Carer (Daughter), Interview 15

"at first it was hard because the weather wasn't really great and my Dad didn't understand that you can't get close to people and he's very you know like pats people on the back and shakes their hand. Every time we'd go for a walk."

Female Carer (Daughter), Interview 24

Care homes

Some carers where the PLWD was living in a care home have also expressed uncertainty surrounding the well-being and activity and social engagement levels of the PLWD. With care homes shut off from external contact, all carers were affected in how they could engage with their relative with dementia, being heavily reliant on care home staff providing infrequent telephone updates. Going from visiting the person they care for nearly every day to being unable to seeing them at all also caused carers to worry about what their condition would be once care homes re-open again.

"I feel that without the intensive stimulation that I was giving her that her condition will deteriorate more rapidly than it was before. That's my main fear."

Male carer (Spouse), Interview 43

Theme 3: adapting and having to adapt to the new normal

Acceptance

Some carers and PLWD, particularly PLWD who were living on their own, showed higher levels of acceptance than

others. They accepted the fact that this was the way it had to happen, and were trying to adapt to these new measures of being unable to access support services and see friends and family. Some PLWD who were living by themselves did not appear to be much affected by closures, as they already used social media as forms of remote support and were used to keeping themselves occupied with jigsaw puzzles, gardening, or other leisure pursuits in their own home.

"a couple of weeks ago I just forgot all about the food and everything else because my partner gets all that stuff for me but she's got her own family to look after and children so there's no eggs, there's no milk, there's no tea, absolutely nothing. Things like that were a big worry, but it was only a phone call away but again I cope with it, and I understood what was going on."

Male PLWD, Interview 46

"I suppose I've got used to it, in a way, because there isn't another choice is there, the choice is I could just sit here and look at the wall and I've never done that before, because I've always tried to build up a vendetta against dementia. So I don't want a poxy little virus standing in the way, so the technology I've mentioned I use a lot."

Male PLWD, Interview 08

Limited remote support

Very few people continued to be offered their social support. Some services have adapted in providing remote support in the form of Zoom internet meetings of previous peer support groups. Some day care centres provided regular phone calls with the unpaid carers. However, only few social support services have adapted, and even where remote support was provided, participants did not feel it could make up for the face-to-face socialising and care pre COVID-19. Moreover, not everyone has access to the Internet or knows how to use or can use Zoom, particularly PLWD who are living by themselves and might be in more advanced stages of the condition, or those with different dementia subtypes.

"we miss them, we really really do miss it all. But having our What's app group has meant that we have been kept in touch which, if this had all struck, five or six years ago we would be stuck wouldn't we, we wouldn't have what we've got now erm so we are really lucky that we've got the What's app but we really do miss the personal contact erm with our friends and keeping in touch with how they all are in this awful crisis"

Female Carer (Spouse), Interview 22

"[PLWD] can't engage in video conferencing or anything like that, he doesn't partly because of the vision issues of PCA he doesn't really see the screen or anything like that and he doesn't now give you eye contact when he's talking to you."

Female Carer (Spouse), Interview 31

Discussion

This is one of the first studies exploring the experiences of PLWD and unpaid carers and the effects that COVID-19-related social support service closures have on their daily lives. Findings highlight a variety of significant issues on people's daily lives, without directly being affected by the Coronavirus in terms of infection.

COVID-19 has resulted in a significant reduction in social support service usage in dementia. These sudden changes had a severe impact on most PLWD' and carers' lives. Suddenly losing control over accessing support, which has often been difficult to obtain in the first place before the outbreak, was a frequent worry. This can place a profound strain on PLWD and carers, particularly after the drastic changes surrounding the beginning of the lockdown have been experienced. Not only has the lockdown created higher distress levels for those affected by dementia, but many carers were concerned with the faster deterioration of the PLWD. Carers reported them as less able to remember people and events and also experiencing greater loss of everyday functioning, thus becoming more dependant. This is likely to be due to the lack of mental stimulation, which is linked with levels of cognition in dementia (Woods, Aguirre, Spector, & Orrell, 2012). Recent early evidence into cognitive and behavioural symptomatology in dementia since the pandemic supports this notion (Boutoleau-Bretonnière et al., 2020; Canevelli et al., 2020), posing a large concern for the increased care needs of PLWD. Increased levels of dependency became particularly difficult for those unpaid carers who suddenly had to take over care that was usually provided by paid carers. Considering that paid carers are often only employed when family members or friends need support in caring for someone with dementia (Bremer et al., 2017), public health restrictions due to the virus outbreak have led to increased carer burden in many unpaid carers. This in turn can place a considerable burden on their mental and physical health, highlighting how the pandemic's public health measures not only affect PLWD directly, but also their relatives and friends caring for them. With unpaid carers providing a large proportion of dementia care (Alzheimer's Society, 2014) and thus often suffering from high levels of distress outside the pandemic (Sutcliffe et al., 2017), this study clearly highlights the need for greater support and recognition for already stretched and overburdened unpaid carers.

This loss of control is reflected further in the uncertainty that people are facing by not knowing when social support services will re-open again, and when these do, in what shape and form. As a result of the reported faster deterioration of many PLWD's condition, many carers were worried and uncertain about whether the PLWD would be able to return to previously enjoyed support groups, activities, or day care centres, as their condition may have deteriorated too far to access these services once open again. This is already an issue with existing service provision, as many services are not adapted to the needs of those with rarer or more advanced dementias (Cations et al., 2017). With the additional challenge of when normal social support services are resuming, many carers are becoming even more distressed. Specifically for PLWD in the more advanced stages, carers reported them to be uncertain about public health restrictions and often unable to understand why they were no longer allowed to attend activities and groups. Most PLWD experience short-term memory deficits (Kemp, Philippi, & Phillipps, 2017), depending on their subtype, so retaining new information can be difficult. Thus, daily or weekly routines are even more important as they can be more easily remembered. With public health restrictions in place, these routines have suddenly been

removed, leaving PLWD understandably distressed. Thus, there is a clear need to enable social support services to function again to not place unnecessary additional demands on family members and friends with caring duties, but also to reduce the distress placed on PLWD.

This requires carers and PLWD to adapt to the new normal, which can be particularly difficult for PLWD who do not understand or remember the new public health restrictions, which can also cause aggravations and increased behavioural symptoms due to frustration of not being allowed outside, for example. While some social support services have adapted and provide some form of remote support, such as Zoom meetings or What's App groups, these do not benefit everyone, particularly, older people and those with more advanced stages of dementia who might not always understand how to use technology. The type of dementia can also affect the person's ability to access these types of remote support, as people with Posterior Cortical Atrophy for example have vision problems. Furthermore, the care usually provided by day care centres, and the respite and benefits provided for unpaid carers (Tretteteig, Vatne, & Rokstad, 2016), cannot be substituted by a phone call from the day care centre or a Zoom meeting. There is also a concern that many older people with dementia might have digital illiteracy (Choi & DiNitto, 2013; Hargittai, Piper, & Morris, 2019), therefore further limiting the value of digital remote support. Research into rural and remote dementia care showcases that remote support has been a problem pre-pandemic across the globe (i.e. Bauer, Fetherstonhaugh, Blackberry, Farmer, & Wilding, 2019; Innes, Morgan, Kosteniuk, & Kostineuk, 2011), which is unlikely to suddenly improve. However, public health restrictions might lead to provide better thinking and planning of remote service provision, where beneficial, which can then expand into post-pandemic service provision for people living in rural areas or unable to visit activities in person. Findings from this study clearly highlight that nothing can replace the face-to-face human social interaction and the impact this has on someone's well-being. Therefore, with COVID-19 remaining in society for some time to come, social support services need to find ways to adapt their offer of support and start providing modified ways of supporting PLWD and carers in a safe environment.

Some carers also raised uncertainty about the well-being of the PLWD if they resided in a care home. In the UK, care homes closed down to the public in March, thereby not allowing family members and friends in for their regular visits. However, carers raised concerns as they were unaware how residents were kept active and occupied, due to limited or no direct contact with the PLWD. Since the initial almost global lockdown, some care homes in the Netherlands have been amongst the first to re-open. Allowing friends and family members back in a safe and socially distant fashion has already been linked to improved levels of well-being for residents (Verbeek et al., 2020). However, there are still considerable uncertainties with no national policy guidance in the UK for example on how care homes should re-open, or how to keep residents socially, mentally, and physically engaged. Considering the significant benefits of social, mental, and physical engagement on well-being (Martyr et al., 2018), it is crucial for nation-wide guidance on supporting care homes to provide the best care possible, within adapted COVID-19 parameters.

While our study benefited from a relatively large sample size, there were some limitations. More unpaid carers than PLWD took part, which was due to the difficulties of recruiting PLWD with mental capacity via support organisations. This might have been complemented by recruiting via memory clinics, where PLWD have more recently been diagnosed. However, given the time-sensitive nature of this study, we decided to recruit via support organisations and existing networks in aid of faster recruitment. This might also have resulted in a low number of people who currently do not access social support services, but would benefit from accessing these. Moreover, further research needs to explore specifically the impacts of COVID-19 related social support service changes on carers and PLWD and carers from black and minority ethnic (BAME) backgrounds, the voices of which have been underrepresented in this study despite targeted approaches of BAME groups. This is particularly important given the increased risk factor for COVID-19 mortality for people from BAME groups (Rose, Mason, & Pennington, 2020). Whilst few male carers participated in our study, this is relatively representative of the national and global picture, as the proportion of women providing unpaid dementia care far outnumbers the proportion of men (Alzheimer's Society, 2020).

Conclusions

This is one of the first studies showing the effects of COVID-19 pandemic-related public health measures and closures of social support services on the lives of PLWD and unpaid carers. Our study highlights significant negative impacts that service closures are having on the lives of those affected by dementia. It is not viable to take away vital care any longer, and policy guidance needs to address how activities and day care could be restarted based on individual circumstances in relation to COVID-19 risks and balancing them with the benefits of social support measures. Whilst social distancing may restrict the number of people who can access services at any given time, this needs compensating with flexible solutions, such as improving remote support and using digital technologies, where feasible for PLWD. Our evidence suggests that remote support and digital technologies will not suffice, and need to be supplemented by face-to-face social activities that meet the need of PLWD and carers who as their cognition deteriorates are likely to fail to recognise their peers. This could be achieved by working closely with carer and service provider organisations, to truly capture their experiences and need for support. Given that the pandemic is going to remain an issue for the foreseeable future, with various degrees of imposed and re-imposed public health restrictions, we recommend policy makers adapt social support services to refine the offer to boost accessibility of care and support for vulnerable groups with high needs; of which PLWD and their carers are a large proportion.

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