

'Four walls and a garden': Exploring the experiences of families affected by dementia during the COVID-19 pandemic

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Emily Cousins¹ and Kay de Vries¹

Faculty of Health and Life Sciences, School of Nursing and Midwifery, De Montfort University, Leicester, UK

Karen Harrison Dening

Faculty of Health and Life Sciences, School of Nursing and Midwifery, De Montfort University, Leicester, UK; Dementia UK, London, UK

Abstract

Introduction: When the first national COVID-19 lockdown came into effect in the UK in March 2020, life changed significantly. Some services and social contacts for people with dementia and their families stopped, while others, for example, peer support, moved online. This research explored the experiences of families affected by dementia during the pandemic, specifically those living in the community.

Aims: In partnership with a community dementia charity, this study sought to gain an understanding of the experiences of people with dementia and family carers during the COVID-19 pandemic and explore the impact and implications of lockdown on people with dementia and family carers.

Methods: This was a qualitative study that used semi-structured interviews to collect data from people with dementia and family carers. Interviews were conducted online via video call, individually or within caring dyads. Initially, data were coded, analysed and themed inductively. Additionally, social disruption and social division theories were used to deductively identify patterns in the data to enhance understanding.

Findings: Six distinct themes were identified from the inductive analysis: Routine: *'busy life before lockdown'*; Isolation: *'four walls and a garden'*; Living with restrictions: *'treading on eggshells'*; Discovering positives: *'you are in the same boat'*; Easing lockdown: *'raring to go'*; Heightened uncertainty: *'things have changed'*. Illustrative examples of symptoms of social disruption and division were identified within the data: frustration, democratic disconnection, fragmentation, polarisation and escalation.

Corresponding author:

Emily Cousins, Faculty of Health and Life Sciences, School of Nursing and Midwifery, De Montfort University, Edith Murphy House, Leicester LE1 9BH, UK.

Email: emily.cousins@dmu.ac.uk

Conclusion: Experiences of people with dementia and family carers during the pandemic were mixed, resulting in hopes and worries for the future. Social disruption and social division are relevant frameworks for analysing experiences of COVID-19.

Keywords

dementia, COVID-19, peer support, community, family carers

Introduction

The COVID-19 pandemic, including the resulting guidance relating to social distancing, has had a significant and disproportionate impact on people with dementia and their families who live in the community (Alzheimer's Society, 2020). In the event of infection, older adults and those with pre-existing conditions such as dementia are more likely to experience worse COVID symptoms or clinical outcomes (Jordan et al., 2020). People with dementia may find it more challenging to follow social distancing guidelines and are likely to live with other health conditions or frailty, meaning they are at greater risk of COVID-19 (Numbers & Brodaty, 2021).

In March 2020, the United Kingdom was placed in a national lockdown for the first time in order to reduce the transmission of COVID-19. This required all citizens (except key workers such as health professionals) to stay at home and only go out for essential trips to buy food or for solitary daily exercise. When leaving home, citizens were required to practice social distancing by staying 2 metres apart from others. In addition, certain clinically vulnerable groups including some people with dementia were asked to isolate themselves further and prevent any possible contact with others outside of their household, known as shielding in the UK, which prevented even these essential outings in an attempt to limit any exposure to COVID.

Research has shown that people with dementia and family carers have faced additional mental health challenges during the pandemic. Levels of anxiety and depression increased amongst caregivers of people living with dementia (Altieri & Santangelo, 2021). Family carers also experienced increased levels of stress due to social restrictions and confinements (Cohen et al., 2020). Overcoming this sense of isolation and addressing the resulting mental health needs required innovative means of social interaction, such as remote or virtual contact (Roach et al., 2021).

The day-to-day existence of people living with dementia and family carers was drastically impacted by COVID-19, which was framed by one study as a 'shrinking world' (Talbot & Briggs, 2021). People with dementia experienced confusion at disrupted routines, and a lack of structure led to a loss of meaning and feelings of social isolation. By contrast, some people with dementia felt a sense of safety from staying at home in their social bubbles and being removed from the pressures of daily life (Talbot & Briggs, 2021; Greenberg et al., 2020).

Many community services, day centres and social groups for people with dementia and family carers were closed during the COVID-19 pandemic. This led to feelings of uncertainty and a loss of control (Giebel et al., 2021). Furthermore, service closures meant people with dementia and family carers had less access to support and respite care (Greenberg et al., 2020).

Research aims

This research study was undertaken in order to explore the impact of the COVID-19 pandemic on families affected by dementia living in the community in the UK, including the effects of the resulting public health measures such as lockdown. Bearing witness and producing a testament of

their experiences during COVID-19 helps to highlight positive and negative aspects to consider relating to future care and practice.

This qualitative research study had two main objectives

- to gain an understanding of the experiences of people with dementia and family carers during the COVID-19 pandemic;
- to explore the impact and implications of lockdown on people with dementia and family carers.

In order to meet these aims, and gain as rich an understanding as possible about the experiences of people living with dementia during this time, it was helpful to situate the study within the context of two relevant theoretical frameworks that relate to change and transformation: social disruption and social division.

Social disruption and social division

Social disruption is a term from sociology that describes rapid change which occurs in social life and communities. It can be characterised by crisis, breakdown and a loss of routine, which may affect behaviour, mental health, social relationships, policy and networks (Park & Stokowski, 2009). One example is the social disruption that can arise from rapid growth in urban areas, which can lead to changes in the economy, tourism, jobs, infrastructure, business investment, housing, crime and community identity (Park & Stokowski, 2009).

Social disruption can also be conceptualised as metamorphosis, namely a ‘radical transformation, in which the old certainties of modern society are falling away and something quite new is emerging’ (Beck, 2016). Such disruption, metamorphosis and transformation can transpire in most areas of life, from geography to politics, at varying levels of seriousness and significance, for example, natural disasters, new technology and acts of terrorism.

Closely connected to social disruption are experiences of social division, a theory which relates to the advantages, disadvantages, inequalities and differences that affect citizens (McCarthy & Edwards, 2011). Social division, and disrupted societies, can be defined according to five commonly identifiable symptoms: frustration; democratic disconnection; fragmentation; polarisation; escalation (Itten, 2018).

Symptoms of social disruption, social division and COVID-19

Across the general population, it can be argued that these symptoms of social division and disruption resonate with some common experiences and behaviours of life during the pandemic. Changes to daily life, unfamiliar working conditions, cancelled events, strained relationships and the cumulative impact of small and substantial losses have left many experiencing frustration during the pandemic. In the United Kingdom, this frustration is frequently politicised due to the government’s approach to COVID-19 (Godlee, 2021). In turn, a lack of government guidance, strategy and transparency, alongside politicians breaking their own social distancing rules (Kuenssberg, 2020), has led to a sense of democratic disconnection and mistrust during the pandemic. Moreover, the emerging COVID-19 crisis in care homes, organisations that have been overlooked, undervalued and under resourced by a government that promised greater investment in health and social care, has resulted in further political disconnect between citizens and state (Cousins et al., 2020).

The bereavement and loneliness experienced during the pandemic, combined with the effects of continued social distancing and visiting restrictions, has created a feeling of fragmentation for many, and a lack of social cohesion. Furthermore, emergency public health responses and decision making in relation to COVID-19, for example, the regional tiers system in the United Kingdom, has caused additional fragmentation and inequality (Sally et al., 2020). Consequently, divisions in society have been evident, often fuelled by misinformation, resulting in the population expressing different views towards compulsory masks and vaccines, which has further exacerbated pre-existing social polarisation (Loomba et al., 2021).

Concurrently, it has been well documented that mental and physical health conditions have worsened during the pandemic, which can be viewed as a type of escalation. More people are reporting symptoms of anxiety and depression (Mind, 2020). Given the risk of COVID-19, many have avoided routine appointments which is likely to result in missed diagnoses of other conditions and impact on long-term physical health (Davis, 2020).

In summary therefore, social disruption and social division were relevant theories for framing this study, using data that are specific to the pandemic, people with dementia and family carers.

Peer support and partnering with a community dementia charity

To complete this study during the pandemic, the research team collaborated with a local community charity based in the East Midlands of the United Kingdom, which aims to empower those living with dementia, and improve care, support and wellbeing. The charity assists people with dementia in their co-ordination and delivery of three peer support groups across the region.

Peer support enables those with shared experiences, such as a dementia diagnosis, to offer emotional, social and practical help to each other, in particular by working to overcome some of the challenges that people may experience. Peer support can offer understanding, knowledge and shared learning, helping to improve quality of life, self-management and engagement with services (Keyes et al., 2016).

During the first UK lockdown, the charity's peer support groups rapidly mobilised online to enable some of their members to continue meeting virtually via video call and to take part in activities together. Participants in these online peer support groups, comprised of people living with dementia and family carers, were invited to take part in this research study.

Methods

Ethical approval for the research was granted by De Montfort University's Faculty of Health & Life Sciences Research Ethics Committee (HLS FREC Ref: 3653).

Participants

Twelve participants were recruited to the study through convenience sampling from members of the online peer support groups. Five participants had a diagnosis of dementia: Young-onset Alzheimer's ($n=1$); Frontotemporal dementia ($n=2$); Vascular dementia with Lewy bodies ($n=1$); type of dementia unknown ($n=1$). These diagnoses are diverse, and it is important to recognise that the dementia type may influence the research findings. Seven participants were family carers, namely, spouses or adult children of people living with dementia (Table 1).

Members of the research team attended each of the three online peer support groups to introduce themselves and the study and to invite attendees to participate. Prior to each meeting, the participant information sheet and accompanying consent form were circulated to each member by

Table 1. Demographics of research participants.

Research participants	Number (n =)
People living with dementia	5
—	
Type of dementia	
Alzheimer's disease	1
Frontotemporal dementia	2
Vascular dementia with Lewy bodies	1
Type of dementia unknown	1
Gender	
Male	5
Ethnicity	
White British	5
Age range	
65–69 years	2
70–74 years	2
80–84 years	1
Family carers	7
—	
Relationship to person living with dementia	
Wife to person with dementia	5
Daughter to person with dementia	2
Gender	
Female	7
Ethnicity	
White British	6
Asian/Asian British: Indian	1
Age range	
49–50 years	1
55–59 years	1
60–64 years	1
65–69 years	1
70–74 years	1
75–80 years	2

administrative staff at the charity. Those who expressed an interest were then formally recruited to the study over email. All participants gave informed consent to take part (written or verbal), which was recorded by the relevant researcher. In the case of written consent, participants signed the consent form and returned a scanned copy via email. In the case of verbal consent, the researcher read through each statement on the consent form via video or phone call and invited the participant to indicate their agreement. This process of verbal consent was audio-recorded, and a consent form was retrospectively filled in by the researcher for audit purposes.

Data collection

Data were collected using semi-structured qualitative interviews lasting up to 90 min. An interview schedule was developed by the research team, which grouped questions around three distinct areas:

life before COVID-19; life during lockdown; imagining life after lockdown was lifted. This time-based approach to questioning was selected to enable participants to reflect on how life may have changed due to the pandemic, enabling comparisons across time points to be drawn. Capturing these insights about change and transformation were integral to the theories of social disruption and social division which were used as frameworks to support this study.

Participants were interviewed individually ($n = 6$) or in caring dyads ($n = 6$), according to their preference. In each dyad, the family carer was the spouse of the person with dementia. Interviews took place between August 2020 and February 2021. Interviews were audio recorded and transcribed by the researcher.

Data analysis

The first round of data analysis was undertaken inductively (data led). Interview transcripts were anonymised and coded using a coding table. These codes were then grouped into themes by each author. The researchers then met to triangulate these findings. To ensure methodological rigour, the researchers reflected on how the voices of the participants could be represented, how insights from the data could be interpreted, and any resulting implications or recommendations for professional practice (Tobin & Begley, 2004). Following discussion amongst the research team, the lead author synthesised the themes, which were then verified by the remaining authors to ensure a consensus. Saturation was evident in the codes and themes that were identified. Findings produced a thematic and narrative account of participants' experiences before and during the pandemic, as well as considerations for the future when lockdown was lifted (Braun & Clarke, 2006, 2013).

In addition to this inductive analysis, the research team recognised that applying a theoretical framework to the data, namely, conducting complementary deductive (theory led) analysis, could serve to increase research rigour and enhance understanding (Fereday & Muir-Cohrane, 2006). Theories of social disruption and social division were identified as highly pertinent analytic frameworks for identifying additional patterns in the interview data. Therefore, a second round of data analysis was undertaken deductively, using social disruption and social division theories, and their commonly associated symptoms. In analysing the data, it was unlikely that participants would name the exact symptoms of social disruption and division using the same formal and technical language that was outlined in the introduction. Therefore, during data analysis, these symptoms were occasionally inferred by the research team through synonyms, metaphor or imagery as is permitted by qualitative research (Braun & Clarke, 2013).

Member checking

The research team were invited to share their findings at a dementia seminar series, where the lead author gave a presentation about the study and the emergent results from the data analysis. This seminar was attended by some of the research participants and other people living with dementia and family carers. The discussion that followed gave an opportunity to engage in member checking (Birt et al., 2016), where participants were able to validate the conclusions being drawn from the research. Amongst those that were present, attendees confirmed that the findings reflected their personal experiences. Furthermore, healthcare professionals and practitioners in attendance commented that the findings resonated with their own experiences of supporting people with dementia and family carers during the pandemic. This member checking helped to increase research rigour and trustworthiness of the data analysis.

Findings

Six distinct themes were identified from the inductive (data led) analysis and named using verbatim participant quotations: Routine: *'busy life before lockdown'*; Isolation: *'four walls and a garden'*; Living with restrictions: *'treading on eggshells'*; Discovering positives: *'you are in the same boat'*; Easing lockdown: *'raring to go'*; Heightened uncertainty: *'things have changed'*.

'Busy life before lockdown' relates to participant experiences before the pandemic, and provides a context to the subsequent data. *'Four walls and a garden'*, *'treading on eggshells'* and *'you are in the same boat'* are themes that describe experiences during lockdown. *'Raring to go'* and *'things have changed'* offer insights about imagining life after lockdown.

Through deductive (theory led) analysis, it was possible to identify illustrative examples of frustration, democratic disconnection, fragmentation, polarisation and escalation in the data: the symptoms of social disruption and division. These symptoms provide additional depth and understanding that help clarify and consolidate some of the themes (Table 2) and are reported as part of the thematic analysis.

Routine: 'busy life before lockdown'

Life before COVID-19 was recalled in positive terms, with most participants stating that they missed how things had been before. The past was often described as *'good'* and *'happy'*. Participants were socially and emotionally well connected, enjoying loving relationships with friends and family, as well as the opportunity to travel and enjoy hobbies. In this regard, it is possible to infer that this sample of participants were, on the whole, *'living well'* with dementia prior to the pandemic.

Discussions frequently focused on how busy life had been before COVID-19:

'I had a very busy life before lockdown...I went to the gym, I went swimming. I was just busy'. (Family carer 4).

'So we've always been really busy, and we've always sort of enjoyed seeing people' (Family carer 7).

Being socially active with friends was a common activity that contributed to these busy lifestyles. This socialising took place during outings and day trips, shared activities and in each other's homes:

Table 2. Themes identified in the data and corresponding symptoms of social disruption and division.

Themes (inductive analysis)	Symptoms of social disruption and division (deductive analysis)
1. Routine: <i>'busy life before lockdown'</i>	
2. Isolation: <i>'four walls and a garden'</i>	•Fragmentation •Polarisation
3. Living with restrictions: <i>'treading on eggshells'</i>	•Frustration •Democratic disconnection
4. Discovering positives: <i>'you are in the same boat'</i>	
5. Easing lockdown: <i>'raring to go'</i>	
6. Heightened uncertainty: <i>'things have changed'</i>	•Escalation

'We used to go out in the car and have a drive round. We used to go and have a cup of coffee with some friends' (Family carer 3).

In some instances, participants were busy with groups or projects relating to dementia or dementia care:

'And we've also been quite involved in the dementia world' (Family carer 7).

'We've said yes to every bit of research that's ever been offered, and it's been fascinating'. (Person living with dementia 5).

Participants also reported spending lots of time with other members of their family, which involved a range of activities, for example, socialising, travel and caring responsibilities. There was a sense of families supporting each other with tasks associated with day-to-day living as well as needs arising as a result of dementia:

'I do all the main medical appointments with my mum, and alongside other family members' (Family carer 1).

The experience of being busy was perhaps more prevalent amongst family carers, an observation that was made by one participant with dementia:

'She's a bit of a social animal, and she's out and about meeting people and things a lot more than me' (Person living with dementia 5).

Alongside these busy lives, there was also a clear routine and structure in day-to-day life before the pandemic. These routines related to daily living, such as mealtimes, as well as weekly commitments, such as attending certain groups or activities on different days:

'Before COVID, really, we were very much in a set routine with mum which was helpful for her because then she ... she was more likely to be aware of what was happening.' (Family carer 1).

As lockdown ended this sense of busyness, routines were lost and disrupted, which some found challenging:

'It's the different, out of routine, and every day it's dementia.' (Family carer 3).

In some instances, this absence of structure and less opportunities for different activities made dementia feel more prominent in daily life.

Isolation: 'four walls and a garden'

Life during lockdown was viewed in primarily negative terms. It was described as '*bad*', '*terrible*', '*horrendous*' and '*absolutely awful*'. However, there were also glimmers of positive experiences, relating to meaningful engagement with each other or resulting from the online peer support networks and associated activities.

Isolation was evident in many forms in the data: loneliness, abandonment, low mood, depression, imprisonment and loss. Participants reported missing the usual occasions for social contact and

stimulation, as well as opportunities to leave the house and engage with the world. Underpinning the experience of isolation, it was possible to infer a general sense of disempowerment, as personal freedoms and choices were curtailed.

Most of the participants felt socially isolated during lockdown, which took a toll on their mental health. Some experienced the isolation in quite physical ways, in relation to their sense of space and surroundings. Unable to leave the house, some individuals reported feeling trapped:

*'One of the major things I think was a problem, was the isolation. It's just awful. Um, you know, **four walls and a garden** is just, you know, really, bad.'* (Person living with dementia 1).

'Yeah, at times it was very, very difficult. Because you, you feel trapped.' (Family carer 3).

Accompanying the isolation, there was an overwhelming sense of loss regarding life during lockdown. This loss was often evident in relation to activities that people would usually be enjoying, for example, going out, travelling and eating in restaurants. There were also consequences attributed to these losses, in some cases depression:

'You need to go out and see life and if you're not able to do that, the depression starts to come in. It's almost like a black cloud over you and every morning you wake up and that black cloud gets bigger.' (Person living with dementia 1).

'Sometimes four, maybe five times a year we go abroad. So we're really missing all that bit.' (Person living with dementia 5).

Where online alternatives for socialising were available, one participant reported that these alternatives could not substitute for in-person meetings:

'I've missed the personal, and erm...contact, you know...and OK on Zoom and that, but it's not the same' (Person living with dementia 2).

Some participants had experienced a significant bereavement due to COVID-19 during lockdown, the effects of which were magnified because the usual processes for grief and mourning were disrupted due to social distancing, which led to further isolation and a greater sense of loss:

'She [person with dementia] was completely flailing really with the grief' (Family carer 1).

Many services and supports for people with dementia and their families abruptly stopped at the point of lockdown, leaving participants feeling forgotten by society:

'He felt abandoned really. I suppose there was no support there at all. Both of us felt like that.' (Family carer 4).

Related to these experiences of isolation are two symptoms of social disruption and division which were identifiable in the data: fragmentation and polarisation.

Fragmentation was particularly evident in the disappearance of services and a lack of temporal structure during lockdown, particularly for some participants living with dementia, who found it more challenging to distinguish one day from the next without specific activities or events:

'I don't remember, going back, that's the trouble, I can't say it. I, I mean I do things now on Monday, and when it's Tuesday, it's a different day. You know? You don't remember what you did yesterday because there's no real sort of an effort to it.' (Person living with dementia 3).

Two family carers described the emotive experience of visiting a relative with dementia during the lockdown restrictions. The imagery of these visits evokes isolation and fragmentation:

'Well, I went to see him one day with a friend and they said 'oh, sorry we can't let you in, we've got lockdown' and that changed things dramatically because I couldn't go in, I couldn't sit with him, I couldn't hold his hand, I couldn't read a book with him. All I could do was visit him through a window' (Family carer 5).

'My sister and I just alternated every day and took her food and put it through the window. It was like...and I would be outside looking through the window, watching her like a prisoner eat her own meal.' (Family carer 2).

Polarisation can be defined as a division into distinct and contrasting groups. In this respect, the act of shielding during the pandemic, and dividing into household 'bubbles', caused a type of polarisation:

'Because he was shielding, I had to be shielding with him as well...So I, you know, I didn't dare bring anything back, so I was isolated as well. So all we had was like the children came and we had garden visits. And that was awful, because not being able to hug them – we're a very huggy family.' (Family carer 4).

'I mean you try and have a good time at home but most of the time it's, same as I say, half the family come round here, and half the family can't' (Person living with dementia 3).

These descriptions of social distancing and shielding, where a family is split into distinct groups, provide examples of physical polarisation and isolation.

Living with restrictions: 'treading on eggshells'

As participants reflected on the hardship of their personal experiences during lockdown, in particular the absence of provisions and policies for families affected by dementia, a few expressed feelings of anger and frustration. Frustration is a symptom of social disruption and division and was a common response from participants regarding the reality of living with restrictions during lockdown.

Sometimes anger and frustration were expressed indirectly, for example, *'it's not fair'*, or the use of euphemisms, that implied that frustration was close to the surface during lockdown:

*'So we had a bad patch where he was just really, really down...and it was like **treading on egg shells** every day with him'* (Family carer 3).

Anger and frustration also resulted from the changes and restrictions that COVID-19 caused, which were harder to accept for people living with dementia:

'Since lockdown I've got the time to think about things and I can get quite angry about it [lockdown].' (Person living with dementia 2).

'She wasn't able to do any of that either afterwards, so she got quite angry at times with the COVID, not because of COVID, but the impact of it' (Family carer 1).

One family carer explained the need to suppress frustration when coping with the stresses and exhaustion of caregiving during lockdown, which suggests these emotions were experienced more commonly than they were released. As such, some participants were feeling pent-up frustration during lockdown:

'And of course I can't, you can't get angry with them [person living with dementia]' (Family carer 3).

Feelings of frustration were evident for a number of reasons, including the loss of prompts and orientation provided by a daily structure, and the missed enjoyment of taking part in activities:

'Every day was the same. And that I found was frustrating for him, because he used to distinguish days with what he's doing' (Family carer 3).

One participant in particular was angry at the inequitable way people with dementia and family carers were treated through the pandemic, namely, the absence of government support and consideration:

'The government have completely obliterated people [with dementia] from their list, and not made anything available or even recognised them...there hasn't been enough to stimulate him, and...that's just the government that's at fault...I don't think the government even looked at carers or people with dementia, that were shut in. And yeah, it was a bad fault.' (Family carer 4).

This sense of injustice is an example of democratic disconnection, namely, a loss of trust and belief in the government, which is another symptom of social disruption and division.

Discovering positives: 'you are in the same boat'

Alongside the negative experiences of lockdown, some participants reported that there were also positive experiences relating to lockdown. A source of positivity was reflections relating to the online peer support groups that participants were attending during lockdown. It was clear that this group activity was greatly valued, and the connections and activities provided were extremely helpful. The peer support groups helped participants to stay engaged and purposeful, providing opportunities for friendship and reciprocal support:

*'You just feel as though, you know, **you are in the same boat**...[the group] has kept me, my thoughts, pretty, pretty much, totally on what can I do for the group. So, that for me, has been the biggest diversion.'* (Person living with dementia 1).

'Yeah, and he's really enjoyed that...it was the other members that we've got to know since we've been on the zoom. And we've made real friends with them haven't we? Through the zoom.' (Family carer 4).

'The thing is that if we didn't have these [the groups] it would be a bit bleak I think. I think all the online things, they do at least give you a feeling, you know, that you are still part of a community.' (Person living with dementia 4).

Several participants reported that they had appreciated the slightly slower pace of lockdown life, as this had allowed them to spend some quality time together at home, enjoying their hobbies, without the pressure to be attending external events or groups:

'This has been one of the real positives of COVID.' (Family carer 7).

'Dug the garden...I work with [name of family carer] doing a bit of gardening, and it's clearing up and whatever...it's been an enjoyable sort of time, without rushing about and just keeping a steady pace on what you did' (Person living with dementia 3).

However, there was also a recognition that this quality time may only be possible for those living with another person:

'Lockdown is better if you've got company, a bit of time together. It makes a huge difference I think.' (Person living with dementia 5).

The online groups offered an opportunity for people to chat about how they were feeling, as well as take part in different activities such as games and crafts. This combined approach proved very effective in offering emotional sustenance as well as enjoyment:

'That's been a big help, big support, just being able to speak to someone who is in the same position as you.' (Family carer 6).

'He thoroughly enjoyed it – so that's what we give him every week. And he loves doing it' (Family carer 3).

'But you just carry on the best way you can, you know, and do what you can' (Person living with dementia 3).

These positive experiences also led to an admirable spirit of resilience. It was evident that the benefits of peer support, which included *'confidence'* and *'willpower'*, underpinned examples of stoicism.

Easing lockdown: 'raring to go'

Looking ahead to life after lockdown elicited a range of responses. Participants spoke of *'anticipation'*, *'hope'* and *'normality'*. There was a sense of longing for the future, as well as concerns about what might lie ahead. Broadly, there was anticipation for life after lockdown:

'I'm raring to go. I just feel as though I am held back...I've got so many things in my head that I would love to do and the moment Boris [Johnson] says that we can do these things...every day will be spent doing, organising, arranging' (Person living with dementia 1).

Some participants were looking forward to socialising, seeing people face-to-face and attending events. Holidays and travel were discussed frequently, and it was clear that this would be a priority once restrictions were eased:

'I want, obviously I want to get back into the meetings...so hopefully I will be able to go out and...talking to people...you know, different conferences and that sort of thing you know.' (Person living with dementia 2).

'Well yeah. I mean, it's going on twenty holidays abroad!' (Person living with dementia 3).

However, there were also some concerns about the feasibility of travelling abroad after such an extended period of staying at home:

'I don't know how we'll manage travelling' (Family carer 7).

Amongst the family carers, there was a recognition that caring for people with dementia during the pandemic had been challenging. Several therefore expressed a desire for self-care once that was possible:

'So that's the biggest thing that I want when we get back to normality is to be able to do more things I want to do. Which will give me a bit more time to myself... Away from the dementia.' (Family carer 3).

'Well to get my ladies back together again, and you know, have the meeting and share what we've been doing and things...And just generally get back to fitness really.' (Family carer 4).

Family carers spoke about wanting time to look after their own needs and prioritise their own health, which had not been as possible during lockdown.

Heightened uncertainty: 'things have changed'

Alongside the eagerness for lockdown restrictions to be eased, there was also a sense of uncertainty for the future amongst participants, including concerns about emerging from the confines of their home and recognition that life would not necessarily be as it was before COVID-19. This theme chimes with the final symptom of social disruption and division, that of escalation, namely, a sense that irreparable changes may have occurred during lockdown:

*'I think I've got more, I've got worries about it...so **things have changed** a lot for us. So we've got to manage that. Also, I think we haven't seen people, and how are we both going to react to that.'* (Family carer 7).

One family carer was concerned about adapting to life out of lockdown, for example, leaving her husband alone in the home once lockdown restrictions were lifted. The family carer made the point that this is particularly challenging within the context of financial cuts to community services, as it would no longer be possible to have a volunteer visit the house to spend time with her husband while she runs errands:

'I think he will miss the company. Because I've been with him twenty-four seven, for the last four, five months.' (Family carer 4).

Several family carers made references to people with dementia '*deteriorating*' during lockdown, and believed their dementia had got worse, or escalated, due to a reduction of socialisation and stimulation:

'[She] definitely deteriorated in different areas' (Family carer 1).

'But then, whether it is lockdown or whether it's his Alzheimer's getting a little bit worse I don't know but, he was, he knows he was forgetting a few things more and the concentration and the understanding of things' (Family carer 3).

However, one participant was uncertain as to whether the deterioration was the result of the isolation or that the condition had worsened as part of disease progression:

'It could be that he has got worse. There's no way of telling until we've got out of it' (Family carer 3).

This escalation of behaviours and symptoms caused some worries about life after lockdown, in recognition of the changes that had occurred throughout the pandemic.

Discussion

Other research conducted during the pandemic similarly sought to identify the impact of lockdown on people with dementia and family carers living in the community. Early studies from the United Kingdom (Alzheimer's Society, 2020; Tuijt et al., 2021) are in keeping with the findings reported here. One survey showed that lockdown has impacted on the symptoms of dementia, namely, concentration, memory loss and agitation (Alzheimer's Society, 2020). This echoes the social disruption concept of escalation as discussed in this research (Itten, 2018), specifically a sense that dementia symptoms were becoming more challenging. This finding was replicated by other research (Talbot & Briggs, 2021). However, by contrast, in another study, some family carers felt that the deterioration of people with dementia was in-step with the expected disease progression, or potentially that the proximity of life during lockdown resulted in a heightened awareness of their relative's health which gave the impression of worse symptoms (Tuijt et al., 2021).

Moreover, some people with dementia and family carers experienced strain in their relationships, with participants reporting exhaustion, irritability and difficulty in attending to their own needs (Alzheimer's Society, 2020; Tuijt et al., 2021). Others experienced higher levels of family carer stress due to the demands of caregiving during the pandemic (Cohen et al., 2020). This affirms the social disruption symptom of frustration (Itten, 2018), which was also identified in this study. This frustration often stems from fear, anxiety and uncertainty – emotions frequently reported in pandemic research (Altieri & Santangelo, 2021; Giebel et al., 2021) – which reaches a 'boiling point' as people experience an 'us and them' mentality (Itten, 2018). Participants also reported a need for self-care, recognising that this may help to overcome some of these emotions.

Loneliness and isolation were also significant themes in other research (Roach et al., 2021; Alzheimer's Society, 2020; Tuijt et al., 2021), with a recognition that people with dementia, in particular, were more likely to feel these emotions (Numbers & Brodaty, 2021). Again, these findings from other studies emphasise the relevance of social disruption theory, in this case feelings of social fragmentation and polarisation (Itten, 2018) resulting from shielding and lockdown. A loss of confidence and a sense of fear were pandemic experiences for people with dementia identified in other research (Alzheimer's Society, 2020; Tuijt et al., 2021), but not explicitly reported in this study.

Early surveys from Spain (Lara et al., 2020), Italy (Canevelli et al., 2020) and Japan (Suzuki et al., 2020) show that experiences of people with dementia and family carers were similar to those reported in the United Kingdom, namely, relating to worsening symptoms, impacts on physical and mental health, and particular hardship for those with a diagnosis of frontotemporal dementia.

Inequalities during lockdown

Salient in this study, which appeared less explicitly in other research, was an awareness amongst some participants of the inequalities and injustices experienced by people with dementia during lockdown and the pandemic. One possible explanation could be that the nature of peer support provides participants with an opportunity to reflect on their shared experiences (Keyes et al., 2016), which in this instance, may have led to an awareness of personal rights and a spirit of advocacy.

Where this political narrative may have been lacking in other comparable qualitative research, it has been evident in UK media commentary throughout the pandemic. The solidarity of peer support camaraderie identified in this study's data, expressed by the image of '*being in the same boat*', was re-framed in one news article suggesting that everyone is experiencing the same pandemic storm, but attempting to ride it out in different boats (Patel, 2020). This alludes to the inequalities experienced by people with dementia which have been exacerbated during the pandemic (Patel, 2020). Indeed, such inequality is a key feature of social division theory (McCarthy & Edwards, 2011). Inequality within this context of social division can relate to differential treatment, unequal access to resources and life chances (McCarthy & Edwards, 2011) – all of which have been evident quite literally for people with dementia during COVID-19.

Criticism and dissatisfaction towards the government for their handling of the pandemic has been reported in other healthcare publications (Godlee, 2021; Scally et al., 2020) and was palpable in the data for this study. These examples show a clear democratic disconnection, another key symptom of social disruption theory (Itten, 2018).

Coping with uncertainty during COVID-19

More generally, previous research cites COVID-19 as a leading cause of heightened uncertainty amongst the population, which could result in significant mental health challenges such as mood disorders and avoidant behaviours (Kesner & Horáček, 2020). A sense of heightened uncertainty relating to life following COVID-19 is also evident in the wider literature relating to people with dementia and the general population. In a similar qualitative interview study, researchers identified 'ongoing uncertainty' as a key theme describing the experiences of people with dementia and family carers following an initial easing of lockdown restrictions (Hanna et al., 2021). This uncertainty, and related stress, was largely attributed by participants to the widespread closure of support services in the community, for example, Day Centres and sitting services (Hanna et al., 2021).

In a slight contrast, another study specifically involving people with dementia with Lewy bodies and family carers, found that family carers experienced exacerbated uncertainty *during* the pandemic, leading to stress and anxiety (Killen et al., 2020). Uncertainty related to a range of circumstances, including availability of prescriptions and not knowing how long lockdown would last (Killen et al., 2020). These findings relating to uncertainty were evident in other research (Giebel et al., 2021), as were the negative effects of disrupted routine (Greenberg et al., 2020).

However, living with heightened uncertainty could prompt citizens to develop positive adaptive coping strategies. For example, one study showed that during COVID-19, people with dementia and family carers found new ways to connect which deepened existing relationships. Furthermore, some prioritised self-care and took part in new or creative activities (Tulloch et al., 2021). These conclusions echo findings from this study. Some participants reported finding gratitude in renewed opportunities for spending quality time together, while others enjoyed the craft activities that were arranged during the online peer support sessions. One family carer recognised that she would benefit

from time for self-care, and wanted to implement this as a positive coping strategy, but this was simply not possible due to her care responsibilities.

These positive adaptive coping strategies can be interpreted as constructive examples of transformation and metamorphosis (Beck, 2016) and illustrate how social disruption can lead to benefits as well as negative impacts.

Implications for practice

This study bears witness to the experiences of people with dementia and family carers – narratives that are particularly important given the well documented inequalities facing this vulnerable population (Alzheimer's Society, 2020). Consequently, the experiences recorded here could help to inform responses to care, policy and practice in the event of future COVID-19 outbreaks or other pandemics. The following recommendations could be considered when planning future services.

First, delivering online activities for people with dementia and family carers can provide entertainment and social connection. In particular, this could help to broaden access for those who are shielding or unable to attend events in the community. Second, it is important to recognise the significance of online peer support groups for people with dementia and family carers, which provide an opportunity for group discussion, information sharing and emotional support. Third, it is crucial to ensure that the needs of people living with dementia and their family carers, who reside in the community, are not overlooked when planning and commissioning services.

Limitations

Given the diverse dementia diagnoses of the participants, it would have been interesting to reflect on the extent to which the dementia type may have influenced participants' experiences of the pandemic. For example, those with frontotemporal dementia may have experienced more significant behaviour changes during lockdown. Or, in the case of a person with Lewy body dementia, being confined to the house with less opportunities for movement may have accelerated the Parkinsonian features associated with this diagnosis. However, due to the sample size in this project, it was not possible to conduct this analysis without inadvertently revealing the identity of participants amongst members of the peer support group who may be aware of each other's diagnoses. For this reason, quotes were not attributed more specifically than 'Person living with dementia'. It would be interesting to consider the experiences of those living with different types of dementia in future research, using a study design that would permit this more easily.

Participant recruitment favoured those with access to technology, so the research does not include people with dementia or family carers who were unable to attend online peer support groups. While the resulting participant numbers are small, the purpose of the study was not to draw generalisable conclusions, so to that end, the number of participants were sufficient to gain a rich understanding of their experiences.

The study context is specific to experiences of COVID-19 at a certain point in time, with most interviews taking place prior to the second and third national lockdowns in the United Kingdom. Conducting interviews at different time points may have changed participant responses.

It is also important to consider that the experiences recorded in this study are not necessarily entirely attributable to the COVID-19 pandemic. And furthermore, some of these experiences of life during lockdown are perhaps not unique to people with dementia and family carers. Additional research would help to clarify these points.

Conclusion

This study demonstrates that the experiences of people with dementia and family carers have been mixed. Feelings of loss and isolation were common, while some participants appreciated new opportunities for quality time together throughout lockdown. All recognised the benefit and value of online peer support during this time. There were both hopes and concerns about the future.

Participants experienced social disruption and social division throughout the pandemic, resulting in feelings of frustration, democratic disconnection, fragmentation, polarisation and escalation, due to the pandemic's impact on supports and services. This study stands as a significant testament to the experiences of people with dementia and family carers living in the community during the COVID-19 pandemic.

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ORCID iDs

Emily Cousins  <http://orcid.org/0000-0002-7775-9117>

Kay de Vries  <http://orcid.org/0000-0002-0141-1392>

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Emily Cousins is a Research Fellow at De Montfort University, United Kingdom. Emily is a multi-disciplinary dementia researcher with a background in arts interventions for people with dementia, research in care homes and end of life care. Her PhD research sought to define the component parts of arts interventions for people with dementia, to understand how they 'work'. She produced a classification and common language to support their description, explanation, simplification and communication. Emily is currently working as a Research Fellow for the international consortium mySupport study, funded by the Alzheimer's Society. This research is taking place in care homes across Europe and Canada and is implementing an intervention to support the family carers of people with dementia regarding advance care plan decision-making at the end of life.

Kay de Vries is Professor of Older People's Health at De Montfort University, United Kingdom. Kay has a nursing background with a career ranging from Public Health Nursing in a remote part of New Zealand to specialising in palliative and old age care in the UK. She has a strong interest in virtue ethics, specifically humility and generosity. Kay has held a number of research grants both in the UK and in New Zealand and her research expertise is predominantly in end of life, old age and dementia care; in acute, community and care home environments. Examples of recent research projects include; experiences of caregivers of people with dementia on acute hospital admissions and providing end of life care; assessing for risk of abuse, neglect and loss of dignity for people with dementia in care homes; she has been involved in the development of a number of training resources for healthcare providers of dementia care. Kay is predominantly a qualitative researcher and has expertise in all qualitative research methodologies but is also experienced in using mixed methods approaches. She has developed and led a number of postgraduate research programmes and

supervised a large number of MSc and PhD research students. She holds three research affiliate positions in the UK, USA and New Zealand.

Karen Harrison Dening has over 40 years' experience in nursing, most of those being in dementia care in a variety of settings and contexts. For the past 13 years, she has worked with Dementia UK and is now the Head of Research and Publications. She came to the 'research world' late in her career. Appointed to a Consultant Nurse position the opportunity arose for a sponsored PhD. She thus gained her PhD at University College London in 2014 focusing on advance care planning and end of life care in dementia. She has several honorary academic positions at UK universities. Through her role at Dementia UK, she is a collaborator, co-applicant and expert member of several NIHR, Alzheimer's Society, ESRC research studies, such as; PRIDE, SEED and PriDEM. Her research interests are dementia care, case management, carer resilience, palliative and end of life care and advance care planning. As well as her academic work, Karen was a past NICE committee member for both the original dementia guideline and its recent refresh and is currently a member of the committee developing the adult carer guideline.