



“The Pandemic is Just Happening on Top of a Pandemic for Us”. Unpaid Carers’ Experiences of Lockdown in the UK: A Thematic Analysis

RESEARCH

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ABSTRACT

Context: With reduced access to medical and social support during the COVID-19 pandemic, the level of support provided by unpaid carers over the lockdown period in the UK was higher than ever. However, the experience of unpaid carers during this period is often overlooked.

Objective: The aim of this study was to explore the question ‘what has been the experience of unpaid carers during lockdown?’.

Method: Eighteen unpaid carers, caring for a family member(s) with physical, learning, mental health, or behavioral disabilities, were interviewed about their experience of lockdown in the UK. Thematic analysis was utilized.

Findings: Three overarching themes created: (a) The value of support, (b) Non-stop care, and (c) Risk to health. A central theme of mental health was also created and discussed across the three overarching themes, rather than individually, due to its extensivity. Support for unpaid carers during the lockdown became more important than ever due to the higher risk to physical and mental health (of both the carer and dependent) and the lack of respite available.

Limitations: Due to volunteer sampling, the evidence in this report is largely based on the perspectives of female carers’, with all but two participants being female.

Implications: Findings raise implications for prioritizing the return of in-person medical appointments post-pandemic and ensuring the continuation of support services for unpaid carers during a pandemic.

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KEYWORDS:

Unpaid carers; COVID-19; coronavirus; family carers; informal carers

TO CITE THIS ARTICLE:

Moultrie, E, Mallion, JS and Taylor-Page, C. 2024. “The Pandemic is Just Happening on Top of a Pandemic for Us”. Unpaid Carers’ Experiences of Lockdown in the UK: A Thematic Analysis. *Journal of Long-Term Care*, (2024), pp. 14–27. DOI: <https://doi.org/10.31389/jltc.156>

1. INTRODUCTION

Unpaid carers usually care for a partner, family member or friend, with many also juggling other responsibilities, including paid work (Carers UK, 2019a). There are an estimated 13.6 million unpaid carers in the UK, with 4.5 million of these becoming carers since the COVID-19 outbreak (Carers UK, 2020a). Unpaid carers provide essential support to people with learning, physical or mental health needs but are often ‘unseen’ by health and social care systems (Carers UK, 2018; Manthorpe et al., 2022; Phillips et al., 2020; Pickard, 2015). Their contribution to society, however, should not be underestimated. A 2015 report from Carers UK revealed that care provided by unpaid carers is worth £132 billion a year (Carers UK, Bucker & Yeandle, 2015)—a figure almost equal to the cost of a second NHS (Carers UK, 2015). Despite this, only paid carers were recognised by Clap for Carers during the first stages of the ongoing COVID-19 pandemic (Wood & Skeggs, 2020), leaving the contributions of unpaid carers unrecognised and widely unknown. Moreover, the full impact of the COVID-19 pandemic on unpaid carers is likely still unknown, and qualitative research detailing the experiences of unpaid carers during this time is sparse.

The first case of COVID-19 was identified in Wuhan, China, in December 2019, and since then the virus has become a global pandemic (Wang et al., 2020). At the time of writing, COVID-19 has caused over 14.9 million excess deaths globally (World Health Organization, 2022) and 175,484 in England and Wales (Office for National Statistics, 2022). To reduce the spread of the virus, governments around the world put in place various social distancing rules. On 26 March 2020, a ‘lockdown’ was imposed in the UK, ordering people to ‘stay at home’, and a further two national lockdowns were imposed in November 2020 and January 2021, with some level of restriction existing throughout and beyond this period (UK Parliament, 2021). Many people in need of care were classed as ‘high-risk groups’ (Health Service Executive, 2023) in the context of the COVID-19 pandemic. People over 70 or with an underlying health condition were considered ‘vulnerable’, and people with particular health conditions (e.g., immunodeficiency conditions) that put them at very high risk of serious illness from COVID-19 were classed as ‘clinically extremely vulnerable’ and added to the Shielded Patient List (Department of Health & Social Care, 2021). Those shielding were told to stay at home and not leave the house (even for shopping or leisure), which meant unpaid carers were relied upon to provide more support during this extended lockdown period, whilst also facing risks of infection for themselves and/or the person they cared for.

For reasons that included social distancing guidelines, staff shortages, travel bans and fear of infection, most formal and informal support for unpaid carers was limited or cancelled (Lorenz-Dant & Comas-Herrera, 2021). This

included social support groups, access to respite care, contact with social services and face-to-face medical appointments. Carers experienced more isolation than ever, and recent research has found the reduction in social support during this period was significantly associated with reduced levels of well-being in carers (Giebel, Lord et al., 2020). An online survey conducted by Carers UK (2020b) found over 50% of participants felt ‘overwhelmed’ and agreed that they were worried of ‘burning out’. The health and well-being of an unpaid carer is not only important for their own quality of life but also that of the person they care for. As the individual receiving care often has complex and immediate health needs, these can frequently be put before needs of the carer. There is strong evidence to suggest, however, that caregiving affects the mental health of caregivers (Smith et al., 2014; Willner et al., 2020), and it should be considered that de-prioritising carers’ needs could create a cycle whereby caregiving leads to requiring care.

During the lockdown, the UK saw a rise in unemployment and a huge shift towards working from home (Su et al., 2021). When asking 1,230 unpaid carers who had paid employment before the pandemic, 17% reported having since lost or given up their job or no longer being able to work (Carers UK, 2020b). This has both financial and personal implications; when unpaid carers remain employed, they feel more financially secure and experience higher levels of social inclusion and happiness (Eurofound, 2015). Where carers can do both, caring can instil a sense of purpose and the opportunity to provide support to a loved one (Bourke, Pajo & Lewis, 2010), whilst work can offer respite from caring and occupational fulfilment (Bruns & Schrey, 2012). However, this is not always easy or possible and hugely depends on the level of care needed.

In contrast to the wealth of research on combining paid work and care, there is little research on carers who balance caring responsibilities with working from home (WFH). Considering research highlighting the increase in parental caring responsibilities and domestic work for those WFH, and in particular women (Craig & Churchill, 2020; Power, 2020), it could be expected that unpaid carers have faced a similar rise in the level of care they are giving, despite maintaining working hours at home. Rogers et al. (2021) explored experiences of mothers whose children had intellectual disabilities during lockdown and reported that juggling WFH with home-schooling and care responsibilities contributed to their burden of care and own mental health problems. Some mothers, however, described positive experiences and unexpected benefits that came out of lockdown. For some, the elimination of daily pressures (e.g., commuting) and the absence of worry that came with knowing where the person they care for was and what they were doing led to a reduction in stress, which may be echoed in the experiences of unpaid carers.

Unpaid carers had to make many important decisions about their caring roles which informed their experiences of lockdown. Giebel, Hanna et al. (2020) explored decision-making processes of unpaid carers of persons living with dementia (PLWD) in relation to receiving paid home care during the pandemic. The report found the central reason for cancelling paid care was fear of transmitting the virus, highlighting the increased responsibility taken on by unpaid carers, and the lack of confidence in preventative measures taken by care staff, such as inadequate personal protection equipment (PPE). Both this study and the previously mentioned study by Rogers et al. (2021) looked at the experiences of carers who care for people with a specific condition (i.e., people with dementia in Giebel, Hannah et al.'s study and children with intellectual disabilities in Rogers et al.). The current study, however, has chosen to use a sample of participants who care for people with a variety of different needs, including physical and mental health needs, with the hope that this more accurately reflects the level of variability in the experiences of carers.

One benefit of taking a qualitative approach is that this variability within human experience can be represented, examined, and used to inform future policy. During a pandemic, however, an epidemiological approach is often taken by scientists and media to understand its distribution and determinants (Morabia, 2020). Although essential, this data-driven, quantitative approach means details of human experience during these challenging periods in history can be overlooked. This was highlighted by Teti, Schatz & Liebenberg (2020) when discussing the importance of including qualitative research during the COVID-19 pandemic. They argued that epidemiologic models cannot always account for cultural, social and psychological factors of people's behaviour during a pandemic and that qualitative methods can help to understand needs of vulnerable or marginalised groups during a health crisis.

With this in mind, the current study aims to shed light on experiences of unpaid carers of people with physical, mental health or learning needs (rather than a specific sub-group of carers) during lockdown—a group who may have been disproportionately affected by the pandemic but also whose contribution in society often goes unseen. The study takes a critical realist approach, interpreting the data using thematic analysis and utilising qualitative methods to produce research grounded in human experience which acknowledges the broader cultural context and explores the question, 'What has been the experience of unpaid carers during lockdown?'

2. METHOD

2.1 PARTICIPANTS

There were 18 participants interviewed for the study, ranging from 27 to 75 years old. Two of the participants identified as male and the other 16 as female. Consistent

with past research (Etikan, Musa & Alkassim, 2016), the sample was purposively selected to find participants who fit the criteria of being (a) over 18 years old and (b) a carer of another person(s) with learning, physical or mental health needs. Consistent with the criteria for the UK government's carer's allowance, participants had to spend at least 35 hours a week caring for another person. Convenience sampling was used to recruit participants via social media and through existing contacts, using a short advert asking the reader to get in touch if they wished to participate. This advert was also shared by several organisations with links to unpaid carers on their social media pages or in their newsletters. The initial target number of participants was 10, which was later increased to 18 in order to gather more data. In order to avoid research bias (which can be a limitation of convenience sampling), there was no incentive given for participating in the study, and all participants who volunteered to be in the study were interviewed. Information regarding ethnicity was not collected in order to adhere to stipulations specified as part of ethical review. Participant demographics can be found in Table 1. Consistent with articles included in the review of the literature above, the term 'intellectual disability' is used throughout to mean the experience of 'significant limitations both in intellectual functioning and adaptive behaviour as expressed in conceptual, social, and practical adaptive skills' (Schalock et al., 2021: p.2).

2.2 DATA COLLECTION

Interviews were conducted either online using a video conferencing software or via telephone, based on participants' preference. In-person interviews were not offered to be sensitive to participants concerns regarding the pandemic. All data was gathered between May 2021 and February 2022, with interviews lasting an average of 60 minutes. The interviews were audio recorded and transcribed verbatim. Semi-structured interviews were used due to their flexibility and versatility (Kelly, 2010) so qualitative data could be gathered which was rich in detail but not confined to a rigid set of questions. An initial list of questions was created by the first author, which was discussed with the second author and edited to ensure questions were both sensitive and exploratory and addressed the research question. Using questions as a guide rather than a script, this enabled interviewers to ask follow-up questions based on the participant's response, producing data which may have otherwise gone undiscovered had a more structured method been used (Polit & Beck, 2010).

2.3 ETHICAL CONSIDERATIONS

The study received ethical approval from London South Bank University Ethics Committee, and the project was consistent with the ethical principles of the British Psychological Society (2018). The salience of ethical

PSEUDONYM	AGE	GENDER	RELATION TO INDIVIDUAL RECEIVING CARE	AGE OF INDIVIDUAL RECEIVING CARE	REASON FOR CARE
Jim	27	Male	Husband	27	Physical
Marnie	51	Female	Mother	26	Physical
Cassandra	29	Female	Partner, Partner of their father	50, 21, 19, 17	Intellectual/mental health/physical
Sarah	74	Female	Wife	79	Mental health/physical
Justine	54	Female	Mother	26	Intellectual
Dawn	58	Female	Wife, daughter	59, 87	Mental health/physical
Kellie	59	Female	Daughter-in-law	82	Mental health
Vicky	60	Female	Mother	26, 28	Physical/Intellectual
Gail	63	Female	Mother	29	Mental health
Trudy	70	Female	Wife	91	Mental health/physical
Carmella	32	Female	Wife	31	Physical
Catherine	75	Female	Wife	83	Physical/mental
Eloise	54	Female	Daughter	71, 84	Physical/mental
Janet	50	Female	Daughter	75, 77	Mental health
Lynn	Preferred not to say	Female	Daughter	79	Mental health
Maya	67	Female	Daughter	92	Mental health
Simon	39	Male	Husband	40	Physical
Susy	44	Female	Mother	12	Intellectual/behavioural

Table 1 Participants' demographics.

considerations in relation to qualitative research was recognised by emphasising participants' freedom of choice, protecting their identity and being open and honest (Arifin, 2018). During recruitment, participants were asked to contact the researcher directly, rather than on a public forum, to protect their identity. They were thoroughly briefed at the beginning of the study and gave written and verbal informed consent, meaning they were fully aware of the details of the study and any potential risks. It was emphasised to participants that they could withdraw for three months following the interview without giving a reason. At the end, participants were debriefed and sent an email signposting support services surrounding unpaid caring. Upon transcription of the interviews, participants were given pseudonyms and any identifiable information was removed. Original voice recordings were then deleted.

2.4 DATA ANALYSIS

A qualitative approach was taken to gather data that was rich in detail (Denzin & Lincoln, 2011), making it an appropriate method for understanding needs of a vulnerable group during a health crisis (Teti, Schatz & Liebenberg, 2020). Reflexive thematic analysis (TA) was used to analyse transcripts of participants' interviews, using Braun and Clarke's six phases of TA as a guide

(Braun & Clarke, 2006; Braun & Clarke, 2019). TA is a method of identifying and organising patterns in data whilst not requiring strict adherence to a particular theoretical framework (Clarke & Braun, 2013; Clarke & Braun, 2014). This allows the researcher to choose a theoretical framework that fits their approach to data analysis, which in the present study was a critical realist perspective. In critical realism, it is understood that individuals construct their own social realities, but these are inherently influenced by cultural and historical elements (Sims-Schouten, Riley & Willig, 2007). In the context of the present study, it is understood that whilst meaning can be derived from recorded experiences of unpaid carers, these experiences have been impacted by cultural influences, in particular the ongoing pandemic and governmental/societal responses.

Keeping in mind that they should be applied flexibly to fit the research question (Patton, 1990), Braun and Clarke's (2006) six phases of TA guided the analysis, which was inductive and began with a familiarisation of the data. This involved transcribing all 18 interviews and reading them through several times, noting initial observations or reflections. The transcripts were then 'coded', with features relevant to the research question within the data being distilled and labelled at both a latent and semantic level. Demonstrating intra-rater reliability

(Saldana, 2011), each researcher coded the data then re-coded at a later time point, establishing consensus and consistency between the two timeframes. Furthermore, to ensure inter-rater reliability, or triangulation, each researcher independently coded the data. Following this, group meetings occurred where codes were discussed and themes were developed. This is consistent with good practice recommendations (Boyatzis, 1998; Scharp & Sanders, 2019) and is congruent with the constructivist paradigm (Golafshani, 2003). In cases where there was any difference in researchers' opinions, discussion led to a resolution.

Patterns and recurring concepts within codes were then observed to collate all codes into potential 'themes'. An inductive approach was taken here, allowing themes to be determined by the data. Themes were then reviewed and refined into a 'mind map', which allowed the researcher to identify links between themes and recognise where any theme may not accurately represent the coded extracts or the entire data set. Finally, chosen themes were refined and defined by pinpointing their 'essence' and naming them in a way that reflected this clearly and concisely. To help with this and to ensure themes were an accurate representation of the data, supporting examples from the data set were collected for each theme.

2.5 REFLEXIVITY STATEMENT

Experiencing the COVID-19 pandemic firsthand and hearing about the ramifications it was having on people all over the world, we felt this was an area of research that was not only current but extremely important. As young and financially secure individuals, we recognised our experiences of the pandemic may not accurately reflect wider experiences of people over this period, and throughout this research we were conscious to keep this in mind. We were mindful of being sensitive and putting our own experiences to the side, giving participants a space to talk openly about their viewpoints.

I, the first author, do not have direct experience of caregiving. Therefore, it could be suggested that I am not able to fully understand participants' experiences (Fontes, 1998). However, it has been argued that a researcher who is personally unfamiliar with the subject area may provide a different viewpoint that is able to unlock novel findings (Berger, 2015). One reason for this is that being an 'outsider' can elicit detailed responses from participants who try to improve the researcher's understanding of the topic. Furthermore, researchers have argued that an 'outsider' perspective enables more criticality during analysis, as those with an 'insider' perspective could assume an interpretation confirming their own experiences (Tinker & Armstrong, 2008).

However, we were in a unique position, whereby I (second author) have personal experience of relying on an unpaid carer throughout the pandemic. As Greene (2014)

suggests, the insider perspective enables some degree of pre-existing knowledge which helps development of interview schedules and understanding of data. Similarly, familiarity with the participant group reduces the risk of 'culture shock' when listening to participants' experiences. Yet, risks associated with a solely insider perspective include subjectivity and bias, whereby the researcher makes assumptions based on their own experiences (Chavez, 2008). By combining insider and outsider perspectives, we drew on benefits of both. For example, discussion at the research development stage improved quality of interviews, whilst discussion at the analysis stage reduced subjectivity associated with a solely 'insider perspective'.

Although I (third author) am not a carer for a person with disabilities, I am a single parent of a young child and have some insight into the experiences carer-participants discussed, albeit not to the same extent. For example, I knew there was no one else available to provide care if I contracted COVID-19. This was demonstrated in interviews I carried out, where participants would compare our situations or use parenting as a metaphor to communicate their experiences to me. These conversations did not occur across the entire dataset; therefore, it is important to reflexively consider and acknowledge my role as interviewer as an active participant influencing and co-producing the knowledge elicited (Hsiung, 2008).

3. FINDINGS

This study explored the question, 'What has been the experience of unpaid carers during lockdown?' Thematic analysis resulted in the creation of three overarching themes: (a) value of support, (b) non-stop care and (c) risk to health. These themes all directly relate to a central theme of mental health; rather than discussing this as an individual theme, 'impact on mental health' is fed throughout the three themes above. Exploration of these themes and links between them are presented in a thematic map below (see Figure 1).

3.1 VALUE OF SUPPORT

Carers had access to varying levels of support throughout lockdown, which appeared to impact on their well-being and mental health, as well as that of the person(s) they cared for. Within this theme, there were three sub-themes identified: (a) social support groups, (b) support from family or friends and (c) accessing medical support.

3.1.1 Social support groups

Cancellation of in-person social support services for carers and/or the individual receiving care, in line with public health measures, left many carers feeling isolated and abandoned: 'When lockdown came, I lost my

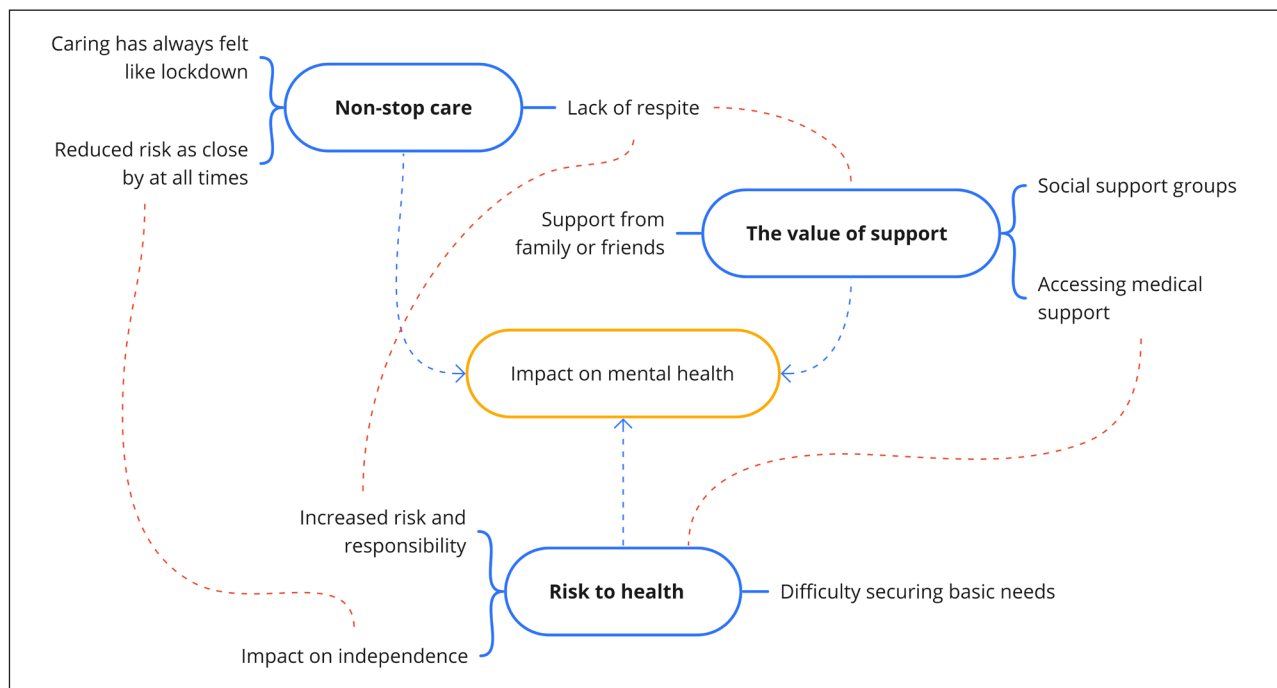


Figure 1 Thematic map demonstrating the themes, sub-themes and relationships between them.

dementia cafes, and I didn't have anything at all' (Trudy). Carers benefited socially from attending groups aimed specifically at carers, but also those aimed at the person they care for. Maya described how she found satisfaction from speaking to other carers at her mum's dementia groups pre-lockdown: 'In some ways that's quite nice to carers because you get to chat to other people.' As well as missing out on the social side of groups, carers described how the cancellation of support groups for the individual receiving care increased their caring workload; as Cassandra highlighted, the person she cared for 'relied on me a lot more, sort of to keep him boosted really', and Lyn commented on how the day centre her mother attended 'shut overnight', instantly increasing the amount of unpaid care her mother needed. For solo carers of people with particularly demanding needs (e.g., complex physical/mental health needs requiring round-the-clock care), support groups provided structure to the day-to-day routine, with their absence leaving carers feeling lost: 'We lost all the structure, and we also lost the social side of things' (Dawn). For some carers, such as Susy, 'Routine and structure is really important for me,' suggesting access to social support groups was essential for maintaining mental well-being; without it, they felt unsupported and less able to cope with their caring roles.

Social interaction was an important part of carers' identities, allowing them to feel like more than 'just' carers, rather social beings with outside relationships and commitments unrelated to caring roles. The sense of loss over social activity is prominent in Trudy's statement, 'I really felt like there was nothing, nothing to look forward to. [...] But now, to be honest, now every day is fairly similar' (Trudy). Critically, it seems that she has become

used to this repetitive 'new normal', which raises the questions of whether it may be a challenge returning to a life with more interaction and commitments when the pandemic is over and whether this will impact on her future capacity.

Some support groups for carers continued to offer online services, including phone calls or virtual meetups, throughout the pandemic. Most carers who received this reported finding this helpful, having gained a sense of comfort that 'there was somebody at the end of the phone' (Marnie). However, there was consensus that digital alternatives did not provide the same opportunities for human connection as the in-person support groups that were possible pre-pandemic.

3.1.2 Support from family or friends

Where carers were not part of formal support groups, they named family or friends as providing emotional or practical support: 'not like formal support groups like that, more just kind of a, a friendship group' (Jim). For carers with a close friend or 'great circle of friends' (Eloise), being able to chat with someone (albeit in a socially distanced manner) provided much-needed levity, acting as a protective factor for continued mental well-being: doing carers 'a lot of good ... they'd sit there in the chair wrapped up in a rug and I'd sit halfway up the stairs and we'd take about an hour having a bit of a laugh and that was actually very nice' (Sarah). The importance of this support was also highlighted by Catherine, who could not see anyone when providing end-of-life care for her husband, reflecting 'that's when it would have been good to have someone come in, just to talk to, to have a cup of coffee with you and pass the time with'.

Multiple carers, however, expressed that they did not feel able to fully confide in their friends for fear of burdening them with their problems:

I always feel like I can't really burden them with it. I can't really go there with it because it's too awful. (Dawn)

I always feel very guilty about burdening somebody else with problems because they've got problems of their own. (Trudy)

You tend to try and just get on and not moan too much. (Maya)

These feelings of guilt and being a 'burden' seemed to isolate carers and reflected a tendency to deflect when it came to the gravity of their problems. Importantly, a difference was seen between carers with and without formal outlets of support. Specifically, feelings of guilt and burdening was not expressed by those with formal outlets. This demonstrates the importance of enabling carers to receive adequate formal support, even when they have the support of friends or family, and how it becomes even more important during a pandemic due to increased isolation.

3.1.3 Accessing medical support

The way people experienced medical support changed drastically during lockdown, with most appointments moving online or via phone. For carers in regular contact with their General Practitioner (GP) for the individual receiving care, this had a large impact. As with online alternatives to support groups, most participants missed the human interaction involved in face-to-face GP appointments and disliked feelings of anonymity involved in a phone call:

Sometimes you just need that extra bit where somebody comes and sits, you're face-to-face and you tell them as it is. (Trudy)

He found [not seeing a GP] quite difficult, like mental health wise he prefers to actually see who he's talking to. (Cassandra)

Not only did carers feel face-to-face appointments were valuable for the individual receiving care, but they provided an opportunity for their own needs, both physically and mentally, to be assessed by GPs, which was not as easy on a phone call. Furthermore, frustration felt by carers at the non-sensical use of phone calls was highlighted by Janet's experience: 'I put mom on the phone. He started talking about dementia. She says, "No, I don't have dementia. I don't know why you're talking about this." And [she] put the phone down.' There was also a consensus that although at the beginning of

lockdown there was 'no other way of doing it' (Trudy), participants felt the pandemic was used 'as an excuse' (Jim) to continue phone appointments (rather than face-to-face appointments) longer than necessary because it was 'more efficient' (Trudy) for medical services.

Increased need for medical support was noted by several carers, with lockdown identified as an aggravating factor in a decline in their own or the individual receiving care's, health. Regarding the health of carers, participants commented on the impact of being less mobile during the lockdown: 'I think my health generally got worse because of that' (Justine). For carers who were 'housebound' (Simon) due to shielding, this negatively affected their mental health: 'I was getting really low and was trying to find a way into some sort of mental health support' (Simon). In addition, carers commented on how the lack of face-to-face appointments contributed to the decline in the health of the individual receiving care: 'Pain has been due to not being able to access to his usual therapy because of the pandemic' (Carmella).

For several unpaid carers considering care homes or paid care for the individual receiving care pre-pandemic, lockdown took away some of their options: 'We were going to the hospice the day before lockdown, and because of lockdown they phoned up and said no we wouldn't be able to go. And that was it' (Catherine). This sudden change of plan thrust Catherine into a caring role, making her 'toughen up and get on with it' (Catherine). There was a feeling that media coverage of care homes led carers to believe home was the 'safest place' (Lyn) for the person they care for because of the increased risk to health associated with care homes, which led to an increase in care workload for many unpaid carers.

To summarise the theme of 'value of support', support from friends and family was invaluable over lockdown, but it was also recognised that it cannot fully substitute for formal support, which reduced throughout lockdown. The need for medical support was not fully met by the reduction in face-to-face appointments. It must be highlighted that the three types of support discussed in this theme are not mutually exclusive, and carers who had positive experiences with all three clearly benefited from the combination. The value of support appeared to increase over lockdown, as care became more continuous than ever, which will be explored in the next theme.

3.2 NON-STOP CARE

With a national lockdown imposed, and access to support limited, many unpaid carers found themselves providing relentless round-the-clock care. For some, these restrictions provided comfort, whilst for others, they exemplified constraints that caring had already put on their life pre-pandemic. Within this theme, three sub-themes were identified: (a) lack of respite, (b) reduced risk as always close by and (c) caring has always felt like lockdown.

3.2.1 Lack of respite

Carers found having to ‘constantly be there’ (Cassandra) over lockdown ‘exhausting’ (Dawn) and ‘absolutely relentless’ (Kellie). Many carers’ roles were 24/7, meaning ‘we don’t get an hour to ourselves’ (Janet). Without respite, carers were less able to take advantage of social support opportunities mentioned in the previous theme or to reap benefits of social meetings without the individual receiving care. When asked about respite care, Dawn said she did not know how to get hold of it, but she emphasised how much she had needed it: ‘I never have a break. I’m always on. I’m always the responsible person. I don’t get a weekend. I don’t get an evening. I’m always—like even now—I’ve got half an ear open’ (Dawn).

Although the level of care provided by participants was varied, all participants related to the feeling of being constantly ‘alert’, which held them back from being able to experience any respite: ‘You do live in this heightened sense of peril’ (Vicky). This sense of peril refers to a constant worry over the health of the person they care for, which was further exacerbated by the looming pandemic. Living in a constant state of peril and alertness negatively impacted on the mental health and well-being of the carer. As discussed in the ‘risk to health’ theme below, concern for the health of the individual receiving care led many carers to decide that it was ‘not a good idea to continue’ (Simon) with outside help—reflecting a catch-22 in which carers were forced to weigh up the risk of outside help with the benefits of respite care. With the nature of unpaid carers’ roles meaning they are in the habit of putting someone else’s needs before their own, respite care was not seen as an option during lockdown for many carers.

3.2.2 Reduced risk as always close by

For those caring for a family member who can maintain a degree of independence, lockdown restrictions appeared to provide comfort, as the person they cared for stayed close by and was exposed to minimal risk: ‘She was here, and I felt, you know, I could keep her safe’ (Marnie). Marnie’s notion of being able to keep her daughter ‘safe’ was echoed by Vicky, who said that when her daughter lived with her during lockdown it ‘felt quite safe because we could be very contained’ (Vicky). It is clear they both felt responsible for the health and safety of their daughters, despite both reporting them having highly independent personalities. Although this could be true of many parents, the level of responsibility felt was intensified by their caring roles.

The conditions of the individuals that both Marnie and Vicky cared for were very unpredictable, but they found comfort in feeling they were in control of a situation (knowing exactly what to do or how to react to an emergency). In the context of the pandemic, the level of control they felt plummeted because of widespread uncertainty and risk to health, putting them in a stressful

and uncomfortable position that was only alleviated by having the person they cared for always close by. Critically, this highlights that easing of restrictions may be challenging for unpaid carers who gained a sense of comfort by having the individual receiving care close by throughout.

3.2.3 Caring has always felt like lockdown

For several carers, especially those having to provide round-the-clock care, restrictions imposed over lockdown did not have a huge impact on day-to-day life: ‘In many ways, it hasn’t made a huge difference because our lives have been so transformed anyway’ (Sarah). For many carers, committing to caring roles meant sacrificing their freedom—one carer even described being a carer as a ‘prison’ (Gail). Some carers felt the national lockdown gave people an idea of what it was like to be in their shoes, to live with restrictions and isolation: ‘Carers have been suffering this pandemic for as long as there’s been carers’ (Janet). Trudy also highlighted that ‘during lockdown things got better, because I knew everybody else was stuck in this horrible life as well, because they couldn’t get out either’. This suggests lockdown gave people an insight into the lives of carers and a taste of some of the difficulties they face daily. Importantly, this highlights that undertaking caring roles impacts both mental health and well-being despite, and due to, a pandemic.

Parallels between lockdown and caring were more prominent for carers of people with complex and multiple needs, although one participant who was a carer for someone with autism did comment on how she had been ‘socially distancing for years’ (Justine) and was therefore unbothered by the idea of lockdown. Similarly, some participants seemed unphased and unsympathetic towards lockdown. For instance, Sarah suggested non-carers would just ‘have to get on with it; I’ve had to get on with it [caring], whether I like it or not’. National lockdown meant staying indoors and limiting contact with others, which for some carers meant more care and less outside help. For carers who were already providing 24-hour care, the increase ‘didn’t feel too different from what I was already doing before’ (Susy). Regardless of whether the level of care changed over lockdown, all carers’ roles were impacted by increased risk to health due to the pandemic, which will be explored in the next theme.

3.3 RISK TO HEALTH

The spread and highly contagious nature of COVID-19 meant there was a significant risk to health when leaving the house during lockdown. This risk impacted carers’ lives in many ways, as explored in the following three sub-themes: (a) increased risk and responsibility, (b) impact on independence and (c) difficulty securing basic needs.

3.3.1 Increased risk and responsibility

Carers already take on ‘responsibility way beyond what a normal person would even consider’ (Gail), but during lockdown this increased due to the significant risk to health that COVID-19 posed. For carers, increased risk led to less support which, in turn, raised responsibilities: ‘I think I would prefer not to have that support if it meant not putting them at more risk of COVID, and it seemed likely that it would, having people in the house. I understand why, but it felt like we lost all external support because of it’ (Eloise).

Many carers commented on increased pressure that came with not wanting ‘someone bringing COVID into the house’ (Carmella). As noted in other themes, the degree of change in responsibility appeared to be based on the complexity of the individual receiving care’s condition in combination with the degree of support the carer received. For carers without a support network, there was “‘no alternative’ (Sarah) to care if they got ill themselves, despite the risk of spreading COVID-19 to the individual receiving care. This level of responsibility and risk manifested as existential guilt for some carers, with the fear of giving COVID-19 to the individual receiving care negatively impacting their mental health: ‘I feel guilty about everything now’ (Marnie).

For carers of people who may not be able to understand the pandemic, there was the added responsibility of trying to explain what was going on and how to behave: ‘Everything changed, and we couldn’t explain to her why. And I think that was frustrating for her’ (Kellie). At a time when there was so much uncertainty, some carers felt relied upon to have the answers, whilst simultaneously feeling in the dark themselves. As such, heightened responsibilities and risk-related fears experienced by carers during lockdowns negatively impacted on their own emotions and stress.

3.3.2 Impact on independence

Increased risk to health impacted on the independence of both carers and the person they cared for, with carers making difficult decisions about how to navigate their caring roles during lockdown. For example, Maya recalled how moving in with the individual receiving care affected her work:

I was working from upstairs, [...] but it was very difficult with mum calling me while I was working. And I was coming up to retirement age, and it was just getting very difficult and so I sort of gave up. [...] Whether I would have gone in other circumstances, I don’t know.

For many carers, the increase in responsibility meant they lost independent lives over lockdown, and this was emphasised by easing of restrictions: ‘It’s happening again now of course. Everybody’s on the go. They’re going

here, there and everywhere, and I can’t go anywhere’ (Trudy). Whilst easing of restrictions represented freedom and independence for many people in the UK, this was not the case for the majority of unpaid carers interviewed for this study. Specifically, caring for people with complex health needs meant continuation of shielding beyond national lockdowns, preventing carers from enjoying the freedom of lockdown easing.

Furthermore, carers described wanting to provide support whilst respecting independence of the individual receiving care: ‘You’re wanting to walk that tightrope between supporting them [...] and not interfering when they don’t need it’ (Vicky). One participant described how the person she cares for, who has dementia, can be ‘dangerously’ independent (Kellie). It appeared that carers were eager for the individual receiving care to live as independently as possible, but this resulted in feelings of anxiety and worry for the carer, as the pandemic had introduced more risk to their lives. For many carers, although they felt the responsibility of keeping the person they care for safe, they also felt a certain responsibility to equip them to live as independently as possible, no matter the cost to themselves.

3.3.3 Difficulty securing basic needs

Being in public spaces during lockdown posed a risk to health, making it hard for carers to secure basics such as food and medical care. Most carers avoided going to the supermarket in person by using online delivery. Upon arrival, food deliveries were not without difficulties—one carer commented on how ‘nobody would help me lift it into the house’ (Catherine)—but several carers also commented on how difficult it was to even secure a slot, which was frustrating and tiring:

I’d end up in tears [...] and you just don’t need that (laughs), you know. When you’ve gotta go get somebody up, out of bed and help them get washed and dressed you don’t need to be crying because you’ve managed to get Tesco’s delivery slots. (Marnie)

Although some carers were able to access priority booking or use a ‘carers card’ to shop ‘with NHS workers’ (Dawn) during quieter periods, most participants felt food deliveries could have been ‘prioritised even better’ (Dawn) in order to help carers feel safe and supported.

Multiple carers also brought up their experience with the vaccination system, expressing issues surrounding prioritisation. Specifically, not being able to be vaccinated at the same time as the person they cared for caused ‘a lot of stress’ (Gail). By increasing the amount of time spent in a public space, the risk to health was increased, causing more stress and worry. Other basic medical and sanitary needs were not met for many carers and the individual(s) receiving care, reflecting the strain on the

healthcare system and the extra responsibility faced by carers during this time. Providing end-of-life care, Catherine had to deal with faecal incontinence and had sanitary waste that needed disposing, but ‘they didn’t come for a few days during the first lockdown’, putting extra strain on her caring role. Similarly, Eloise recalls having to source medical supplies to help with her dad’s stoma: ‘We spoke to the stoma suppliers. You can get extra strips to seal it, extra-long strips around the bags to stop that. So, we did all that.’

The themes explored in this report reflect the variation in how unpaid carers experienced lockdown. Support from others was seemingly invaluable, with many carers feeling bolstered by close friends and family. Carers lost access to more formal support, which increased the caring workload. Carers experienced being constantly ‘alert’ and providing non-stop care. The intensity of this care also increased, with risk to health being at the forefront of carers’ minds, making it difficult to access food or have any form of independence. With these factors in mind, it is unsurprising that being an unpaid carer during a pandemic negatively impacted mental health and well-being.

4. DISCUSSION

This is one of few qualitative studies exploring experiences of unpaid carers during the lockdown period in the UK. The lack of restrictions placed on the ‘type’ of unpaid carer (i.e., age, gender, needs of the person they care for) interviewed for this project allowed the study to reflect the breadth and variety of the experience of unpaid carers during this time. Within this variety, three major themes were identified that gave insight into the question, ‘What has been the experience of unpaid carers during lockdown?’: (a) the value of support, (b) non-stop care and (c) risk to health. Each of these themes directly impacted on carers’ mental health and well-being.

Unpaid carers’ experiences of lockdown were heavily influenced by the amount (or lack thereof) of support received. In line with research by Giebel, Lord et al. (2020) that found reduction in social support service hours during lockdown to be significantly associated with reduced levels of well-being in carers, carers in the present study noted extra pressure that these closures put on themselves and the individual receiving care. Giebel, Lord et al. (2020) also noted that lack of support groups for people living with dementia (PLWD) during the COVID-19 pandemic led to a loss in daily routine and structure, leading to faster deterioration of the disease. The current study had similar findings, extending these to carers of people with physical, learning and mental health disabilities, who noted that the loss of structure and routine led to lower moods and difficulties with pain management.

This study aligns with research emphasized the importance of formal care services (Brimblecombe et al., 2018) whilst adding to existing literature highlighting the value of support from friends and family. Although it is not suggested that support from friends and family can be an alternative to formal support, it was clearly highly valued and beneficial for many carers. Conversely, findings did highlight hesitancy in many carers to fully confide in others, spurred on by a fear of being a ‘burden’. This has implications for social care policy, whereby building knowledge on how to support carers in your family or social network could be emphasized, having a positive effect on carers and, in turn, the people they care for.

Another finding that has implications for health and social care policy is the impact of the loss of face-to-face medical appointments. Carers missed human interaction involved in face-to-face appointments and expressed their absence had a detrimental effect, claiming that phone appointments did not enable their doctor to see the ‘full picture’. This could lead to increased need for medical intervention further down the line for the person(s) they care for, but also to poorer recognition of carer needs. Similar findings can be found in research looking at the experience of family caregivers of people with dementia during lockdown (Zucca et al, 2021; Pongan et al, 2021). Despite recent advice that GP surgeries should return to offering face-to-face appointments (Lacobucci, 2021), participants did not seem aware of this, and many carers shared the belief that online appointments were still offered simply because it was more convenient for health services.

Carers reported that caring roles became 24 hours during lockdown due to a lack of respite or distance from the individual receiving care. These echoed findings of Rogers et al. (2021), who found one of the biggest challenges reported by mothers of children with intellectual disabilities during the first lockdown was the lack of ‘breaks’. Adding to the findings by Rogers et al., several participants who provided care to their child in the present study (beyond that of a typical parent-child relationship) expressed gratitude for the close proximity during lockdown, as it gave them a sense of control over the individual receiving care’s safety. For some carers, however, their experience of lockdown was not different to regular life, and they felt their contribution during lockdown was no different. This supports the notion that the work of unpaid carers goes ‘unseen’ (Phillips et al., 2020). Where support for paid healthcare staff was marked with weekly clapping on doorsteps, extensive fundraising (Captain Tom raised £38.9 million for the NHS by walking 100 laps of his garden (The Captain Tom Foundation, n.d.)) and an outpouring of donations of medical equipment (NHS England, 2020), nothing was done publicly to support unpaid carers, leaving carers feeling under-appreciated and ignored.

A large part of unpaid carers' experiences of lockdown was the increased risk to their health and the health of the individual receiving care due to COVID-19. Research by Giebel, Hanna et al. (2020) found increased risk to health to be a central reason behind unpaid carers cancelling paid care. This was echoed in the current findings, with carers sacrificing additional help in favour of reduced risk to health. It should be considered whether more could have been done at a policy or community level to make unpaid carers feel safer accepting outside help, such as increased PPE or testing for the virus. Measures such as these may have helped ease the increase in responsibility that unpaid carers experienced over lockdown.

Another parallel between Giebel, Hannah et al.'s (2020) research and the current study was the difficulty carers faced securing basic needs, including food and medical support. Giebel, Hanna et al. reported that carers were unable to successfully shop online and could not benefit from priority shopping slots, as people with dementia were not classed as 'vulnerable'. Several carers in the current study, and not only those caring for a PLWD, were unable to access priority slots despite caring for someone who was vulnerable, making it harder and riskier to get food. The classification system for vulnerable persons appears to be flawed and should be more considerate of carers and *their* needs, as well as that of the individual receiving care.

As with all psychological research, the current study had some limitations. Although there was a lot of variety in age of participants, relation to the individual receiving care and type of disability, the sample was majority female (all but two were female). However, there are more female than male carers, with a 58%/42% split, respectively (Carers UK, 2019b); using a stratified approach to sampling could have made the sample a more generalisable representation of the population of carers, thus more accurately reflecting carers' overall experiences of lockdown. Furthermore, there seemed to be similarities in the experiences of unpaid carers based on age of the individual receiving care and severity of disability, and so further research could explore this by using selective sampling to choose a group of unpaid carers in similar caring roles to see if this translated to similar experiences of lockdown.

This research provided a detailed account of how unpaid carers experienced lockdown and has shed light on some of the difficulties faced throughout this period, as well as acknowledging some of the benefits. Overall, carers felt exhausted by the relentlessness of providing care during this time and felt unsupported or ignored by the government and health system. Those caring for people with highly complex needs felt more isolated than normal due to the cancellation of social support groups, but they also commented on how their caring role always felt like lockdown to some degree. Considering the impact that living in lockdown had on so many in the

UK, it is with a renewed sense of empathy that we should consider those providing care and strive to implement systems and policies that leave them feeling supported and seen during and post-pandemic.

FUNDING INFORMATION

There was no funding available for this research.

COMPETING INTERESTS

The authors have no competing interests to declare.

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TO CITE THIS ARTICLE:

Moultrie, E, Mallion, JS and Taylor-Page, C. 2024. “The Pandemic is Just Happening on Top of a Pandemic for Us”. Unpaid Carers’ Experiences of Lockdown in the UK: A Thematic Analysis. *Journal of Long-Term Care*, (2024), pp. 14–27. DOI: <https://doi.org/10.31389/jltc.156>

Submitted: 16 June 2022 **Accepted:** 27 October 2023 **Published:** 10 January 2024

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