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Caring during lockdown: Challenges and opportunities for digitally supporting carers

A report on how digital technology can support carers during the ongoing COVID-19 pandemic.



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Caring during lockdown: Challenges and opportunities for digitally supporting carers.



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National Context and Background

At the beginning of 2020, the world began to take notice of a novel coronavirus, SARS-CoV-2. The virus was initially identified in the Wuhan region of China in December 2019. As a result, the disease emerging from the virus became known as COVID-19. COVID-19 would eventually lead to a lockdown of the Wuhan region followed by a later national lockdown of all mainland China. Many Western governments did not believe the COVID-19 epidemic would spread beyond China or, failing that, East and Southeast Asia. Unfortunately, cases began to increase across parts of Europe with nations like Italy facing particularly high incidence rates amongst its ageing population.

On 23 March 2020, all of our lives changed. The consequences of the COVID-19 pandemic, with incidences increasing rapidly across the country, Boris Johnson, the Prime Minister, issued a statement to all of England that people 'must' stay at home starting a nationwide lockdown. The lockdown has impacted all of our lives. Many of us began to work from home when possible. Meanwhile key workers combated the virus and its consequences for society on the frontlines.

Not all individuals felt the consequences of the national lockdown in the same way. Many parents suddenly found themselves caring for school children after schools closed early. Many people already providing care suddenly faced additional challenges and intensity to carry out their care responsibilities to children and adults with disabilities. Strict guidelines for social distancing and shielding people with specific characteristics, including older adults and people with pre-existing conditions, meant that these carers also became more isolated.

Carers develop a remarkable depth of knowledge and skills related to their loved one's condition and their role as a carer. An important source of advice and guidance for carers is peer support; speaking to fellow carers who are experiencing the same issues has a profound effect on the health and wellbeing of a carer. The process of acquiring knowledge and sharing it with others 'in the same boat' contributes to resilience which protects against negative outcomes, such as carer burden (Donnellan et al., 2015).

Mobilise describes itself as 'the tech start-up by carers and for carers'. They are a community driven business working with local authorities and carers' centres to identify, engage and support carers at scale with innovative technologies.

As the national lockdown commenced, Mobilise drew on existing research and established a series of daily 'Virtual Cuppas'. Facilitated by a professional Carer Coach, these Cuppas offer a relaxed, online setting for carers to check in with other carers around the country and discuss the challenges they face each day. The Mobilise methodology includes:

- Identifying a topic or question in advance of each Cuppa to structure the initial conversation (Typical topics focus on personal challenges, coping strategies and practical steps to manage one's wellbeing);
- The application of coaching principles to peer support discussion;
- Guidance for participants on sustainable approaches to peer support;
- Using humour as a way to unlock difficult conversations;
- An 'uplift' activity at the end of each Cuppa.

Each Cuppa lasts 30 minutes and takes place every weekday with times available in the morning, afternoon or evening, depending on the day. Although Mobilise has received positive feedback from its users, it required additional research capacity and expertise to evaluate the efficacy of the platform to address challenges for carers across the country during the national lockdown.

This report describes a project aimed at exploring challenges experienced while caring during the national lockdown and how digital platforms may help alleviate them. The study team analysed transcripts of one such platform, Mobilise's Virtual Cuppas, to address the project's objectives.

- Identify the challenges and resources available to carers during the national lockdown.
- Use this data to evaluate how, and to what extent, Mobilise's Virtual Cuppas platform mitigated these challenges.

To achieve these objectives, the study team developed four research questions:

- Part 1. What specific challenges are carers facing during the national lockdown and other restrictions in response to COVID-19?**
- Part 2. What resources are carers drawing on to manage and adapt to these challenges?**
- Part 3. How effective is the Virtual Cuppa in reducing carers' challenges and identifying novel resources over this time period?**
- Part 4. What are the emergent challenges for using Virtual Cuppas?**

The concept 'resilience' helped organise our understanding of carers' challenges and access to resources during the national lockdown. Resilience is "the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life course, the experience of resilience will vary". (Windle, 2011: 12). Most of what we know about resilience from carers comes from quantitative research methods with a distinct lack of qualitative longitudinal research exploring this same topic (Donnellan, 2017). By following the same cohort of carers through the national lockdown period, the study team gained a more dynamic picture of the challenges carers experienced. The longitudinal character of the Virtual Cuppa dataset helped the study team identify changes in how carers accessed resources, including their participation in the Virtual Cuppa platform itself, and how they developed resilience during the national lockdown and the initial easing of related restrictions.



Research Methodology

Data

Qualitative-longitudinal data was drawn from 96 of Mobilise's daily Virtual Cuppas, between 20th March 2020 and 28th July 2020. A total of 118 participants took part in the Cuppas over this period, with a maximum attendance of 16 carers and minimum attendance of one carer per Cuppa. The average attendance per Virtual Cuppa was approximately six carers.

Each Cuppa lasted 30 minutes, providing approximately 49 hours of data to analyse. Mobilise provided a dataset of transcriptions for each Cuppa during this period. Mobilise had previously audio-recorded and transcribed the dataset for internal quality assurance purposes. They shared this dataset with the study team to carry out secondary data analysis to examine the challenges and resources associated with caring during the national lockdown and evaluate the Cuppa platform.

This data presented an opportunity for the study team to explore carers' experiences during the national lockdown as they participated in Virtual cuppas over a four month period. As the data was not collected specifically for research purposes, it provided an opportunity for the study team to explore individual carers' challenges as a result of increased restrictions in response to the COVID-19 pandemic. To highlight the distinct long-term and routine characteristics of this dataset, the study team refer to it as both **longitudinal** and **naturalistic**.

The study received ethical approval from the University Research Ethics Committee of the University of Sheffield in April 2020. In addition, Mobilise had previously obtained informed consent from all participants of the Cuppas so recorded data could be used for research purposes.

Participants

Thirty members of the Mobilise Virtual Cuppa community responded to a short survey to acquire demographic information. The survey reveals a mix of ages and ethnicities, with the majority of Cuppa participants being white, aged 46 – 65 and living across England and Wales, including: North West, South West, Midlands, South East, South Central, South Wales; but also New York in the USA. The majority of participants reported that they had been providing care to a loved one for more than one year and that care frequency had increased since the start of COVID-19 lockdown (see [Figure 1](#)).



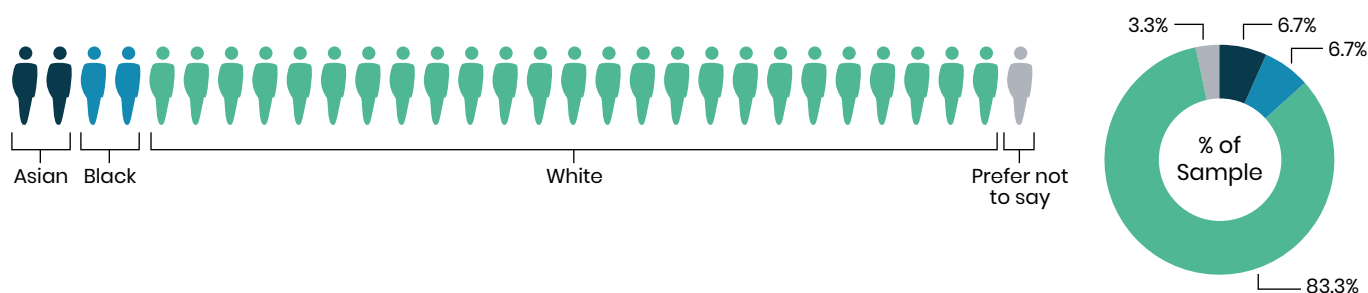
Figure 1. Demographic Characteristics of Virtual Cuppa Participants.

Participant Characteristics 30 people

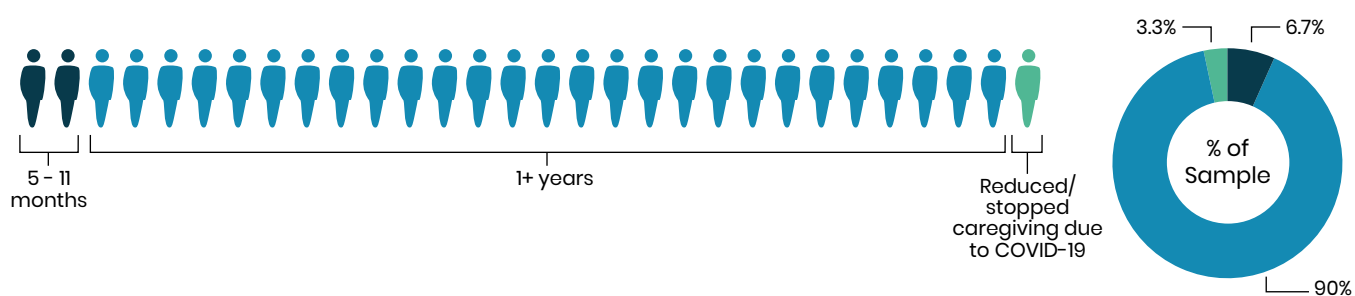
Age



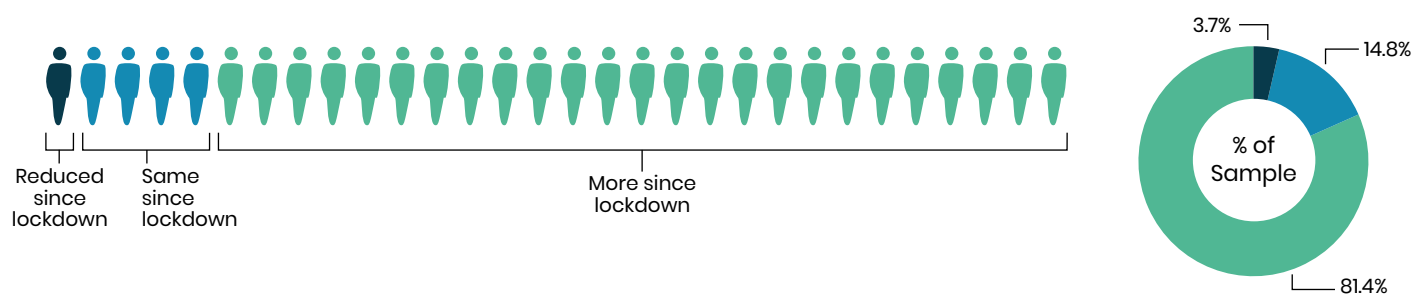
Ethnicity



Care Duration



Care Frequency



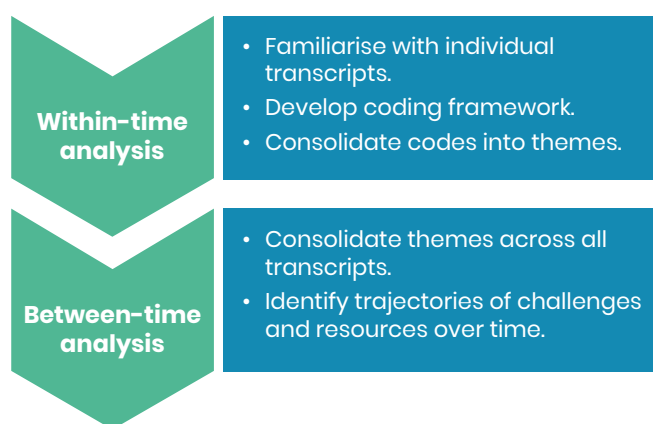
Data Analysis

The study team analysed Virtual Cuppa data using a Thematic Framework approach (Braun & Clarke, 2006; Ritchie & Lewis, 2003). The longitudinal approach allowed us to gain a deeper understanding of carers' experiences including how and why they change over time. The methods have been informed by the consolidated criteria for reporting qualitative studies (COREQ) guidelines (Tong, Sainsbury, & Craig, 2007).

The analysis began on 4th April 2020, and was primarily conducted by three female Research Assistants (RAs), PB, LS and SG, supervised by two male qualitative researchers, ML and WD, for independent coding purposes. All members of the research team were experienced in the use of qualitative research methodologies. The coding framework was managed using a Microsoft Excel spreadsheet comprising the coding for each analysis, alongside Cuppa number, Cuppa date and the topical question posed by the Facilitator during that session. We included socio-political contextual information alongside each Cuppa, including key events and government announcements regarding COVID-19. This allowed us to better understand the nuanced context around our analysis so that the conclusions drawn were ultimately more valid and realistic. Each Cuppa was hyperlinked to the corresponding transcript in Microsoft Word, where participant quotations were tabulated alongside exploratory notes and codes. These methods ensured that the process of analysis was fully transparent.

Holland, Thomson and Henderson (2006) propose that qualitative longitudinal research should involve an initial cross-sectional analysis followed by a longitudinal between-time analysis (see [Figure 2](#)). Due to the constraints of the data source, we are not able to identify individual participants across all of the Virtual Cuppas. Therefore, we treat cases as the assemblage of participants and their discourse mediated through the Virtual Cuppa platform.

Figure 2. Within- and between-time thematic framework analysis.



Within-Time Analysis

The RAs first read the transcripts a number of times to ensure familiarisation with the data. The transcripts were then evenly distributed between PB, LS and SG. The research team met regularly to develop a provisional coding framework and ensure the constant comparison of new data. Over the course of analysis, the RAs added any new codes to the coding framework, and removed any codes that became superfluous. In order to further strengthen the rigour of the findings, a subset of Cuppa transcripts were independently re-coded by the other RA. Any coding discrepancies were discussed until a consensus was reached. The research team as a whole agreed when data saturation had occurred and no new codes were emerging from the data. Codes were then reviewed and consolidated into broader themes relating to the key challenges that carers were facing and the resources they were drawing on to manage these challenges. The final themes were presented to the wider research team who discussed the extent to which they were grounded in the data and identified any omissions or ambiguities in the analysis.

Between-Time Analysis

Once themes had been generated from individual Virtual Cuppas, the RAs conducted a secondary between-time thematic analysis of all Cuppa themes. This allowed us to identify the dynamic trajectory of challenges and resources available to carers over the course of the COVID-19 lockdown period. We followed the same systematic processes outlined in the section above.

Findings

This section presents the findings from our qualitative analyses of the Virtual Cuppa data. Findings are presented in four thematic sections linked to each of the study's research questions:

- Part 1. What specific challenges are carers facing during the national lockdown and other restrictions in response to COVID-19?**
- Part 2. What resources are carers drawing on to manage and adapt to these challenges?**
- Part 3. How effective is the Virtual Cuppa in reducing carers' challenges and identifying novel resources over this time period?**
- Part 4. What are the emergent challenges for using Virtual Cuppas?**





Part 1. What specific challenges are carers facing during the national lockdown and other restrictions in response to COVID-19?

The announcement of a national lockdown on 23rd March 2020 had a profound negative impact on the carers taking part in the Mobilise Virtual Cuppas. In the early stages of lockdown, the carers experienced a great deal of uncertainty and anxiety in terms of what the lockdown would mean for them and their loved ones' functioning. For example:

"My biggest fear, because she has mixed dementia, is that by the time it is all lifted, my Mum will have forgotten me." (25/03/20)

The theme of uncertainty carried all the way through the Cuppa period; carers felt as uncertain in the later Cuppas as they did in the earlier Cuppas. As time passed, the carers' uncertainty led to a perceived loss of control and autonomy and increased apprehension about what the future held. The following carer used the following analogy to capture her experience:

"I feel as if I'm on a wave, you know, and you do not know where that wave is going to throw you next... I'm sort of bracing myself to see where we go next" (23/04/20)

These feelings of uncertainty and loss of control were exacerbated by a perceived lack of information from the national government. The following carer highlights her specific concerns over returning to work:

"We go back to normal, what's that gonna look like? My job might be open, but my support networks might not be, if that makes sense... I sort of go, are we fully back? Are we not back? What if I can't go back straight away?" (08/05/20)

Other carers reported feeling confused by conflicting information from different sources, for example:

"They've told me to isolate from my house as well. But no one sent me a medical, it's only what the nurse had been telling me. I don't know what to do best for my husband or myself. So um, I'm fairly confused." (12/05/20)

A lot of the anxiety caused by uncertainty and lack of information centred on perceived access to essential healthcare services. The following quotes highlight the carers' concerns:

"They've got nothing over there. There's no ventilators, no oxygen, you know... they've got like nothing." **(15/05/20)**

"It's literally been changing every single day. The angiogram wasn't going to happen until August. Now it's been brought forward." **(22/06/20)**

In addition to feelings of uncertainty, the carers felt restricted by government-sanctioned measures such as social distancing and shielding. In the early stages of lockdown, many carers reported social isolation and feelings of loneliness. The following carer captures her experience of restriction and isolation using another analogy:

"It's like a prison. The walls are closing in." **(26/03/20)**

A key consequence of this isolation and loneliness was a desire for social interaction. The following quotes illustrate the carers' desire for affectionate contact and proximity from loved ones that they could not see:

"We can't hug anybody. Nobody. It's just the loneliness you feel between the four walls." **(05/05/20)**

*"I've been on my own and locked down as well. A lot of us have, so, you know, I just said one day 'it'd be nice for someone to make me a cup of tea.'" **(06/07/20)***

The cumulative impact of restriction and perceived lack of information led to carers feeling less motivated than usual. The following carer takes a negative view of her reduced motivation:

"I've been rubbish the last couple of days. Not wanted to do very much. I've slept a lot, which is not like me" **(30/04/20)**

As time passed, the carers' feelings of demotivation challenged existing daily routines that were important to both the smooth running of their household. The following quote illustrates the impact of demotivation on routine:

"I've struggled today. I've only just got around to making my bed and I haven't made it properly. I've not been very mobile today at all. I have to come to terms with the fact that it is going to be like that for a while." **(03/06/20)**

The 'dual role' of carer and wife/husband, or carer and daughter/son, has always been challenging to negotiate. However, the national lockdown and increased time spent at home posed additional challenges to the carers. For example, the following carers describe how the line can blur between work, home and care:

"I have a 'dual role'. I'm a carer for my mum. She doesn't live with me. So that's a bit stressful... I also work for a carer support agency." **(01/05/20)**

"There's no kind of physical divide... and it's kind of all merging into one... So, for me, it's about managing that work from home and making sure that I've got time for everything, including that work life balance." **(15/05/20)**

All of the above challenges take an emotional toll on the carers taking part in the Cuppas. Towards the end of the Cuppas, there is a clear cumulative impact of four months worth of restrictions and increased caregiving responsibilities. This led to feelings of fatigue in the carers, for example:

"I couldn't figure out whether I was ok and just tired... what would make it better for me is having more arms, more legs, more time and more of me really." **(10/06/20)**

Increased fatigue was associated with increased feelings of burden and burnout in the carers, as the following carer describes during one of the latter Cuppas:

"Even though he's not here in presence he still takes up an awful lot of my energy and my time... my brain is fried and i can't think... I just need to have some me-time." **(23/07/20)**

Box 1. Use-Case Profile: Sally's challenges with caring during lockdown

Here we present a use-case profile of a carer who used the Virtual Cuppa, named Sally.

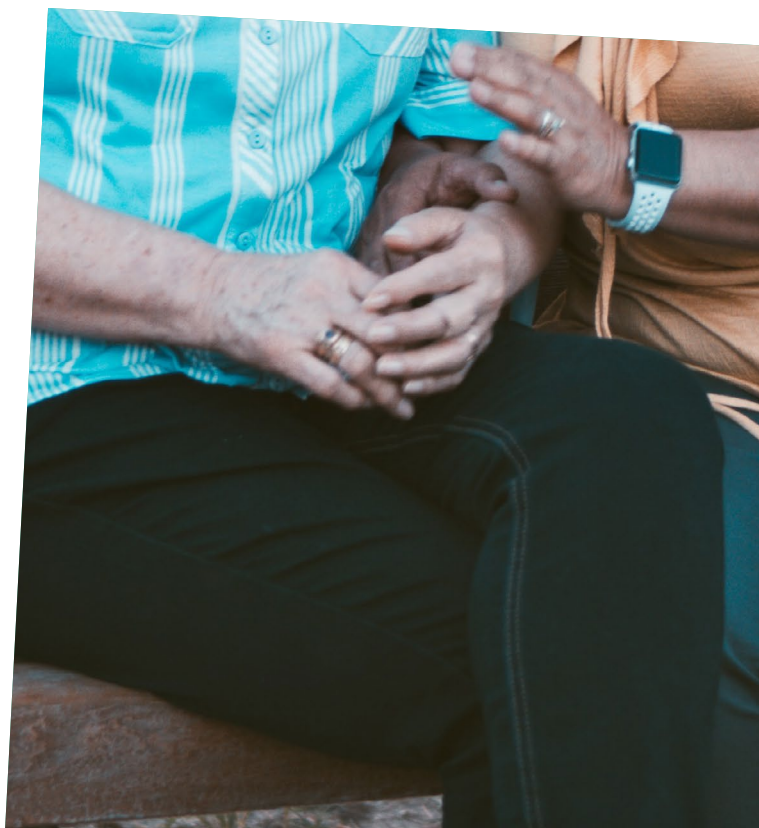
Sally provides care for her adult son. He struggles with his speech, so they communicate by signing. They must travel to access specialist support services.

During lockdown, Sally became concerned about her son's progress feeling it began to reverse. Lockdown also led both Sally and her son to withdraw from their routine activities, increasing their anxiety. To exacerbate these issues, her son's personal assistant changed and they received reduced local authority support during lockdown. In total, these challenges restricted her capacity to leave the house and exercise her independence.

Throughout the findings of this report, we will follow Sally's caring journey during lockdown and the implications of her case for the digital support of carers.



In summary, the carers reported significant challenges during the first COVID-19 lockdown period. Perceived lack of information and social restrictions had a cumulative impact on carers' sense of certainty, control and levels of motivation. Over time, this took an emotional toll on the carers leading to feelings of exhaustion and burden. The following section explores the various ways in which the carers managed and adapted to the challenges identified in this section.



Part 2. What resources are carers drawing on to manage and adapt to these challenges?

Our analysis revealed that carers taking part in the Mobilise Virtual Cuppas quickly began to draw on their own personal assets and a range of community level resources to manage and adapt to the challenges posed by the COVID-19 lockdown restrictions.

For example, despite feeling demotivated in the early part of lockdown, the carers established a new set of routines. The following two quotes illustrate how establishing structure and new routines helps carers to regain a sense of control:

"To get back to a routine gives us a sense of control. Out of the chaos a little bit that we feel that we're in at the moment... My pick is swapping my morning swim for a morning walk." (25/03/20)

"Routine is key for us at the moment. We've got like a semi-structure if you like. But if something doesn't happen, that's ok. If we've got that structure, it keeps us sane." (26/03/20)

Gradually, the carers started to use more active methods of dealing with the lockdown. For example, some carers began to accept the lockdown and viewed their situation more positively and optimistically:

"Although this is a very real situation. There is some hope and it's not all doom and gloom." (25/03/20)

"What keeps you going is the 'light at the end of the tunnel.'" (28/03/20)

The carers were not only able to stay positive but many were able to use humour to deal with the challenges they were facing. This reflected the fact that the Virtual Cuppa was a safe environment where the carers could be themselves. Humour was an essential resource for the carers throughout the whole lockdown period, as illustrated by the following quotes:

"How do I switch off? I tend to have a little word with my boyfriend and he makes me laugh and that helps me relax before I go to bed. So I like doing that. He's my therapy." (28/04/20)

"That was very funny. That good laugh is gonna be good for us, isn't it? Keep the anxiety levels low. They're getting lower. So that's good." (08/06/20)

Over time, the carers also began to manage their frustration and started to make small changes to look after themselves. Self care was an important part of this, as the following quotes demonstrate:

"I decided on a whim yesterday while I was getting my essential shopping to buy some hair dye. So I've got a nice vibrant purple." (30/03/20)

"I don't want to sound selfish. I just want that time to myself. Very important." (22/04/20)

Some of the carers spent their 'me time' practicing relaxation techniques to manage the uncertainty and anxiety associated with lockdown. For example, the following carers used principles of mindfulness and meditation to relax:

"I'm just taking that few minutes out whenever needed. Just taking that second out to breathe because it's so intense trying to plan for every eventuality." (26/03/20)

"I don't have access to a garden, but I can see a garden outside my window. So I use it for like meditation and stuff and being mindful. So I watch the birds and the bees and the wind and the trees. That's one thing that helps me relax." (02/04/20)

Spending time outside with nature, whether that be in a home garden or on a government-sanctioned walk around the park, was a common way for carers to manage their stress levels, for example:

"I think Tuesday's supposed to be beautiful. So I'm going to be doing things in my garden tomorrow. If the weather allows anyway." (04/04/20)

"I haven't been out for about four weeks, which is really, really bad. So for me, getting up this morning, I was like... I'm gonna be really productive. So I went for a walk." (14/04/20)

In addition to their primary caregiving roles, carers received and provided support to others. In the following quotes, the carers highlight the exchange of support to their neighbours and friends:

"Not a lot we can do about the coronavirus but if you can help your neighbour or them help you out, it makes you feel good." **(01/04/20)**

"I can do a bit more phoning friends and just trying to keep connected to people as best as I can." **(27/03/20)**

Peer support in particular became one of the most crucial resources for the carers around this time. The lockdown made face-to-face support between carers impossible but that did not stop the carers from helping each other out online. The following carer describes the nature of this peer support:

"We are on a community Facebook page full of 'moaners'. Generally when somebody wants to say something, we say look, this person needs help." **(31/03/20)**

This sense of community had a profound effect on the carers' wellbeing and spurred them on to continue looking after their loved ones, as the following quote illustrates:

"I think that's what's keeping me going actually is just knowing that the community is pulling together out there and properly falling over themselves trying to do stuff... I feel that if I need something, there's a multitude of people I can rely on." **(21/03/20)**

As time went on and lockdown restrictions began to ease, the carers started to reconnect with family and friends. The following quotes highlight the impact of reconnecting on the carers' wellbeing:

"I actually had a really good weekend... Saturday I went to my cousin's wedding... not seen them for, well, since lockdown, talking about nearly four months." **(13/07/20)**

"It was lovely to see my friends face-to-face as opposed to being on FaceTime or whatever... I was a good day for me, even though I've cried." **(18/06/20)**

"I went to see a close friend who hasn't been able to go out... three of us went and we had such a lovely afternoon... we know each other well, so there was some really rum fun." **(26/06/20)**

Box 2. Use-Case Profile: Drawing on Sally's pre-existing resources.

At the beginning of lockdown, Sally drew on her extensive network of family and friends for support. She occupied her days with silly games, jokes and any other form of humour and fun to ease her anxiety. For Sally, these activities provided temporary reprieve from the challenges of caring. Playing with her son even brought some levity to her role as a carer and allowed her to connect with her son. However, she still struggled with feeling isolated in her home.

Here, we see how Sally has drawn on available resources to help reduce her anxiety. Although they provide some support, Sally still has issues with isolation and a sense of feeling confined to home.

In summary, the carers quickly adapted to the various challenges identified in the previous section. Despite being physically restricted, carers established new routines and adopted positive strategies such as humour and self-care to actively manage their wellbeing. Carers summoned the strength to both receive and provide support to those in need; not just their loved ones, but also members of the caregiving community. Our analysis revealed that the carers were drawing on quantitatively more resources in the later Virtual Cuppas than the earlier ones. This may in part reflect the gradual easing of lockdown restrictions, but it does suggest that the carers were building up their own personal capacity for resilience and their community resources over time. The following section explores the various ways in which the Virtual Cuppa itself facilitated a sense of community over the first COVID-19 lockdown period.



Part 3. How effective is the Virtual Cuppa in reducing carers' challenges and identifying novel resources over this time period?

The Virtual Cuppa system provided an outlet for people to share their experiences – both challenges and triumphs – as the United Kingdom entered into a national lockdown. Some Virtual Cuppas began with breathing exercises and reflection focused on mindfulness techniques and positivity. One participant reflects on how she became motivated to think positively at the start of each day and its impact on her life:

"I read somewhere and I don't know if it was via Mobilise that might have been through you, [name of moderator], about starting the day, and how you've got to welcome the day and really feel and think. I've achieved that one thing if nothing else... to open the curtains and stay yourself upright. Thank you. Yeah, I just thought, you know, I was looking back to how I was and I was thinking, I couldn't move and the curtains are constantly closed. I was demotivated and everything else, but now it's like six o'clock open the curtains and get out of bed." (16/04/20)

As identified in the previous section, carers participating in Virtual Cuppas could often access many community resources and types of individual support. From the

inception of the Virtual Cuppa, participants used the system to share resources they uncovered to support themselves or the person under their care.

"I love the ideas that come out of this. I always come out of these calls, very inspired, very energised, very motivated to do something. So like, for example, have a chat about different resources because one of the things we come up with the other day. Oh, I've got this to share and this and that. And I always come away going, yes. You know what, we're gonna put this together or do this or try this. And so we've come away inspired. I think that's the big thing for me." (09/04/20)

On a separate occasion, a carer commented on the importance of preparing yourself as a carer for any accident after hearing it in a previous Virtual Cuppa.

"I am just studying to do that. Today, I had a course, 'carers emergency response service'. I think it's sensible. Anyway, they updated my care plan with them. And it made me think about getting a package together." (08/04/20)

The 'package' that she refers to here is paperwork that states her daily routine, location of medicines, and any special notes about her care recipient, in case of an accident. She was exposed to this potential resource through her participation in the Virtual Cuppa.

Virtual Cuppas also provided an opportunity for participating carers to share unique perspectives about how they care; something that many carers may otherwise not have been exposed to. This included, for example, participants who shared simple mantras promoting self-care.

"If we say no today, then we'll be able to say yes tomorrow." **(03/04/20)**

Participation in the Virtual Cuppa also provided a space for carers to reflect on how lockdown afforded new opportunities for them.

"I know people are trapped in their house a lot because of the virus. But this is the ideal opportunity to work with your partner to get things done. And one thing I do with my husband because he's had a stroke, it takes him a while to get dressed. So this is ideal for him to take as long as he wants to get clothes on to get dressed to get washed. So it's a good learning opportunity. And we could do exercise together. So it's getting to know your partner a bit more at this time."
(03/04/20)

In the previous quote, one participating carer noted how lockdown allowed her to slow down her routine, which she believes also benefitted her husband under her care. It provided an opportunity for carers to connect with their partners, children and other people involved in care relationships without worrying about the frenetic pace of 'normal' life.

Participating carers found Virtual Cuppas a helpful, if temporary break, from their caring obligations and other everyday responsibilities.

"But these meetings are really helping, so yeah. Yeah, it's really nice. It is really nice. And the other thing is as well, is that I can have an adult conversation." **(02/04/20)**

These early cases highlight a key feature of Virtual Cuppas. They allowed participating carers to share information about available community resources, special offers, and stories to help bring a new perspective to how they made sense of their lives following the start of lockdown. Even after lockdown restrictions eased in the summer, this still featured strongly in later Cuppas in June and July.

"I want to applaud [facilitator] who gave me a one-to-one earlier on in the week. Because I'm now gearing up with [husband] coming out of hospital. So yeah, a big pat on the back." **(17/07/20)**

The previous excerpt illustrates how one aspect that made participating carers feel at ease was the facilitator or, as Mobilise calls them, the Carer Coach. Carer Coaches helped plan each Cuppa around a specific topic or question to generate initial conversations. In later Cuppas, this became more relaxed where participating carers often did not need a prompt to begin the conversation. Carer Coaches, however, also played a role in ensuring people who joined later felt included in pre-existing Virtual Cuppas. They often set up private one-to-one calls to help them integrate. The apparent need to integrate people into Cuppa groups anticipates another feature of the Cuppas. Whereas Cuppas started as a platform for sharing information about available resources, it became a resource in its own right as a form of community-building.

By the time the Cuppas had been running for a month, participants began to gradually feel they belonged in a group.

"Come in and out. You feel like you start to become family, a real sense of a group and understanding. You are learning about other people's difficulties."
(15/04/20)

They identified the benefit of speaking to people facing similar experiences to their own as a carer.

"I think face to face contact is really good because the people you are meeting in the supermarket, you can't get close enough. And you don't know them. And you've got nothing in common with them. At least I'm here. We've got something in common. And we can support each other. I think it's really important that we stay connected. Yeah."
(17/04/20)



Around this time, people also began to feel more comfortable with each other. They shared personal hardships they encountered as a result of caring.

Carer 1: "Thank you for letting me be a hog today on this little madness trip."

Carer 2: "Thank you for being here."

Carer 1: "I think it gets better the more we know each other. It's getting better and people are letting their guard down a bit which is good for carers, I think." (21/04/20)

They even began to share small victories and personal matters not related to caring.

"So I have some very good news to share with you all. Yeah. So I've got a call from work today. So they've extended my contract to July next year. I officially have a job and I am quite relieved." (27/04/20)

By May many of the participants recognise each other and feel comfortable. There is constant laughter throughout each session. They joke with each other and share funny stories about themselves. This has resulted, to a certain extent, in reducing their stress if only for the 30 minutes spent participating in the Virtual Cuppa. Virtual Cuppa has provided a safe space to laugh and share their worries safely.

Facilitator: "What emotion are you leaving with? Or what do you want to leave behind?"

Carer 1: "I'm leaving with an awful lot of love. Okay. Yeah, I think that we are a community and I think we all support each other."

Carer 2: "Absolutely." (14/05/20)

Even when participants felt tired or overwhelmed with caring or other facets of their life, they still took the time to join the Cuppa. Although they may not participate as much as a result of their fatigue, it was important for them to see the people they had come to know over the preceding months of the lockdown.

"Yes, so I'm very tired, very, very, very tired. So if I say words, or they don't come out my brain or my mouth, just ignore me. I just want to see faces. Just wanted to see smiley faces. Lovely to see." (08/06/20)

Despite people moving house or limiting their participation on future Cuppas, participants still identified them as members of the group. It suggests that the online carer communities created by these Virtual Cuppas may extend beyond the limits of digital technology.

"[Carer] has moved to [another town] and does other things as well, but he's still part of the gang." (29/06/20)

As the summer months continued and the national lockdown restrictions eased at the beginning of July 2020, people reflected on their experiences of using the Cuppa. They expressed gratitude for the support they received from Mobilise.

"I do think we have come out all quite well ... on the whole. It's been quite worrying with all the COVID stuff, but you know, we have managed to keep it together. And I think Mobilise has helped me definitely to keep it together." (02/07/20)

Beyond the practical information shared over lockdown, what appeared most important to participants were the relationships they fostered with each other. Information about community resources may have benefited their capacity to continue caring during a public health crisis. However, participants felt particularly appreciative of the other carers they met during the national lockdown. Despite challenges still emerging after the initial lockdown period, it is this sense of community developed over the preceding four months which instils resilience in participants.

"Right now, I have to say I appreciate this group and the I came on quite, quite low sort of thinking about oh gosh, what's [son] going to be doing for two solid days? He's lost those days of when he's not out and I'm gonna lose my respite. You know, it's literally lifted me because I came on quite low and I've been enjoying the laughter." (27/07/20)



Box 3. Use-Case Profile: Sally's support received through Virtual Cuppas

Returning to Sally nearly a month after lockdown, she has begun to participate in a series of facilitated video chats, Mobilise's Virtual Cuppas.

With the Virtual Cuppa, Sally has a platform to share her emotions with other carers. Despite each person on the call having distinct care responsibilities, they share common stories and challenges. Sally looks at the Virtual Cuppa as a 'release valve' where she can unburden herself with people around the country going through similarly challenging circumstances. She feels inspired by other people to continue caring with a new appreciation now aware of what challenges other people face. Sally begins to project renewed resilience.

In summary, participating carers appeared to initially join Virtual Cuppas as a platform to exchange practical information about caring during the lockdown, such as community-based resources. Gradually, carers began to share their perspectives on caring and coping strategies for reducing stress and anxiety exacerbated by the national lockdown. As carers routinely joined Virtual Cuppas, they developed companionship with other carers. First, they talked about their challenges with providing care, then they increasingly shared stories about personal triumphs and challenges in other facets of their lives. By the end of July, carers using the Virtual Cuppa felt a genuine sense of community, or even kinship, with the other members of the Cuppa. They highlighted how participation in the Virtual Cuppa 'lifted' them when they experienced low moods. Virtual Cuppas not only appeared an effective platform to identify and share available resources for carers during the national lockdown, but it became a resource in its own right to develop individual resilience.

Part 4. Emergent challenges for using virtual cuppas

Virtual Cuppas provided a platform for carers to share information and became a resource to develop resilience over time. However, the Cuppas occasionally faced challenges common with many digital platforms.

A few carers experienced issues with trying to access Zoom, the online platform used to hold each Virtual Cuppa.

"It [Zoom] drove my goddaughter mad because we were trying to set it up. She was going to help me, but I couldn't get any further. And that makes me feel so I need to do, but I put it down. I thought oh, I'm not letting this I've got it on all three things, you know, my phone on their laptop." (04/06/20)

For some people participating in Virtual Cuppas, this will be the first time they ever used a programme like Zoom. Some carers may even be using a webcam for the first time as well. This may have impacted the extent to which some people participated on any single Cuppa. When individuals encountered difficulties joining the Cuppa or figuring out their hardware problems, the Carer Coach and other Cuppa participants often tried to help them fix the issue.

"One thing we've all learned is that it never works smoothly, no matter how clever you are. Everybody and I think as a population, people generally are less worried about that. It's not work. You know, this isn't all work. It's not a business meeting that we're having here. And people are quite patient with the technology and people give it a go and more and more people now just go I've never done this before. Oh, it's worked." (28/07/20)

Carers accepted that there would occasionally – and inevitably – be technical problems. However, with patience other Cuppa participants and the Carer Coach could often help people fix these technical problems. As it appears few people consistently and repeatedly experienced technical problems with the Virtual Cuppa, this could signal that Cuppas upskilled the digital skills and literacy of carers.

Box 4. Use-case profile: Sally witnessed unintended challenges of using Virtual Cuppas

Sally has remained an active participant in the Virtual Cuppas for nearly two months. Although she has not experienced any problems using Zoom, the video call software; she has seen some carers frustrated when they cannot manage to join the Cuppa or have technical problems, such as with their camera. Sally, on the other hand, feels empowered by her experience on the Virtual Cuppa. She has decided to take on the responsibility of running her own Cuppa for other carers separately from Mobilise.

Although Sally has not experienced issues herself, a few carers experienced challenges due to low digital literacy. They may be using a webcam or platforms like Zoom for the first time. However, Carer Coaches and other Cuppa participants helped trouble-shoot these technical problems. As a result, Virtual Cuppas appeared to have the unintended consequence of upskilling individual's digital literacy through their participation.

These findings highlight important technical problems that many digital care services and products will encounter. It also raises important questions about the future of Mobilise's Virtual Cuppa.

First, given historical, though infrequent, issues with Zoom, is it the best platform to continue to deliver Virtual Cuppas? Zoom is an inexpensive and widely accessible platform as people can access the call via a sharable link. However, Zoom also received wide media coverage for data security issues at the start of the pandemic based on the company's false statements about encryption, which they have since addressed. Virtual Cuppa participants may not be aware of data security and protection issues. Mobilise must ensure that personal data remains appropriately safe and secured.

With the increasing emphasis on community and friendship in Virtual Cuppas, how can Mobilise ensure new members continue to feel included in longstanding groups? This has not been flagged as a particular issue in the data, but if Virtual Cuppas continue to be offered then new carers may feel like relative outsiders to a well-established group of carers. Carer Coaches may have an increasingly important role to play in the integration of new members.

If Mobilise decides to open up Virtual Cuppas to a wider audience of carers, would they seek input on future developments of their products and services with current users? In other words, is there scope for current Cuppa participants to co-produce future iterations or new services with Mobilise? Virtual Cuppas have already produced a large dataset that identifies challenges for carers during the first lockdown. The study team recommends Mobilise harness this dataset to inform future products and services and test them with their clients.



Conclusion

The national lockdown in response to COVID-19 in the spring and summer of 2020 brought considerable changes in everyone's lives. Carers in the United Kingdom reported significant challenges during this first lockdown. It appeared that a lack of information and social restrictions cumulatively impacted on carers' sense of certainty, control and levels of motivation. Over time, this took its toll expressing itself as feelings of exhaustion and burden.

Despite these hardships, carers quickly adapted to these challenges. Even when physically restricted and socially distanced, carers established new routines and adopted positive strategies such as humour and self-care to actively manage their wellbeing. Carers summoned the strength to both receive and provide support to those in need; not just their loved ones, but also other carers in their community. Our analysis revealed that the carers were drawing on more resources during later Virtual Cuppas than the earlier ones. This may in part reflect gradual easing of lockdown restrictions, but it does suggest that the carers were building up their own personal capacity for resilience and their community resources over time.

Virtual cuppas provided a means for carers to exchange practical information about caring during the lockdown. Gradually, carers began to share their perspectives on caring and coping strategies for reducing stress and anxiety exacerbated by the national lockdown. Carers developed friendships with other carers through Virtual Cuppas. It became a digital space where carers could share their challenges and triumphs in all aspects of their lives. Virtual Cuppas helped to foster a digitally-enabled virtual community, which continued to grow and strengthen despite occasional problems with Zoom and hardware. Virtual Cuppas appeared to exceed its capacity as a platform to share available resources for carers during the national lockdown. It became a resource in its own right to develop individual resilience.

This study benefited from access to longitudinal, naturalistic data shared by Mobilise with the study team. This naturalistic quality of the dataset ensured carers' stories were genuine, not a potential artefact of a survey or interview schedule. The longitudinal quality of the dataset also provided the study team an opportunity

to explore how carers experienced changes over the duration of the national lockdown. Conversely, analysis of the dataset took longer as a result of no prior research tool to frame or organise interactions in the transcripts around particular topics or phenomena of interest for the study. The study was limited in its exclusive analysis of secondary data. The study would have benefited from additional interviews with participating carers for clarification or additional information about their personal circumstances or their experiences using the Virtual Cuppa. In future projects, we intend to use prospective data collection with secondary data analysis to address this limitation.

The findings presented here do not represent all people's experiences of caring during lockdown. There is an increasing evidence of a 'digital divide' in care that disadvantages certain groups who lack the infrastructure and skills to exploit digital technology in their everyday day lives and care arrangements (Wright, Hamblin and Lariviere, 2020). Although Mobilise's Virtual Cuppas do not require the purchase of any proprietary software, some carers may not have access to broadband and a computer or smartphone to access Mobilise's services. Further research is required to discover the magnitude of the digital divide and its impact on carers and care recipients.

This study's findings illustrate the range of challenges and opportunities faced by some carers during the first national lockdown response in the United Kingdom. It explores in granular detail the trials of carers and how they have attempted to adapt and cope during a public health crisis affecting their own wellbeing and caregiving capacity. However, COVID-19 still remains with us. Since the national lockdown ended, regions of all four constitutive nations of the United Kingdom have experienced various levels of localised restrictions. As a study team based in Liverpool and Sheffield, we are keenly aware that carers will continue to face additional challenges as they adapt to living under Tier 3 restrictions as part of the Government's new system of COVID-19 related restrictions. We hope the findings of this report will shed light on the types of challenges experienced by carers in the past, to anticipate and prevent them in further responses to the ongoing COVID-19 pandemic, and other crises that may appear in the future.

Recommendations

In light of the findings presented in this report, the study team makes the following recommendations:

- **Invest in additional support for carers during national crises**, such as a global pandemic and lockdown, which restrict their access to traditional support services and peer support. Carers play a pivotal role in the provision of unpaid support for individuals with disabilities, chronic and terminal illnesses. They need support to ensure they can continue to support others.
- **Invest in innovations and infrastructure that can keep us connected**. Virtual Cuppas highlighted the importance of trusted relationships and community during periods of profound uncertainty. In the absence of face-to-face interactions, many people relied on digital technology to ensure they remained in contact with family, friends and colleagues. However, not all individuals have access to the hardware, software or infrastructure (4G/5G, broadband, etc.) to maintain these connections. Technology not only helps us remain connected with people closest to us but it enables us to connect in new ways and create novel communities as illustrated with Virtual Cuppas.



- **Develop digital literacy programmes for carers**. Some of the participants in the Virtual Cuppas used Zoom and webcams for the first time as a result of their participation in Mobilise's system. If the Government and local authorities will continue to invest in digital technology to support carers, then they must also ensure carers have appropriate instruction and training to use the hardware and software.
- During lockdown, we witnessed a marked uptake of digital technology in health and care; Mobilise's Virtual Cuppas represents one case of this. However, to ensure digital technology remains relevant and fit for purpose as local restrictions ease, businesses and commissioners must ensure they have thought about sustainable options for their products and services, for example, **create future digital support for carers that can bridge analogue and digital communities and support networks**.



References

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.

Donnellan, W. J. (2017). *Providing informal care: How to facilitate resilience in challenging times* (Doctoral dissertation, University of Liverpool).

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health*, 19(10), 932–939.

Holland, J., Thomson, R., & Henderson, S. (2006). *Qualitative longitudinal research: A discussion paper*. London: London South Bank University.

Ritchie J, & Lewis, J. (2003). *Qualitative research practice: a guide for social science students and researchers*. London: Sage.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal of Qualitative Health Care*, 19(6), 349–57.

Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, 21(2), 152.

Wright, J., Hamblin, K. and Lariviere, M. (2020). The potential of technology in adult social care, Sustainable Care Policy and Practice Brief. Sheffield: CIRCLE. <http://circle.group.shef.ac.uk/wp-content/uploads/2020/10/The-Potential-of-Technology.pdf>



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Mobilise is the tech start-up by carers, for carers. They are part of the Zinc Mission 2 portfolio, and are supported by the Paul Hamlyn Foundation. Mobilise is working with local authorities across the country to boost support for carers during the coronavirus restrictions and to increase the identification and engagement of carers.



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