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To cite this article: Sara K. Simblett, Emma Wilson, Daniel Morris, Joanne Evans, Clarissa Odoi, Magano Mutepua, Erin Dawe-Lane, Sagar Jilka, Vanessa Pinfold & Til Wykes (2021) Keeping well in a COVID-19 crisis: a qualitative study formulating the perspectives of mental health service users and carers, Journal of Mental Health, 30:2, 138-147, DOI: [10.1080/09638237.2021.1875424](https://doi.org/10.1080/09638237.2021.1875424)

To link to this article: <https://doi.org/10.1080/09638237.2021.1875424>



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Published online: 27 Jan 2021.



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Keeping well in a COVID-19 crisis: a qualitative study formulating the perspectives of mental health service users and carers

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ABSTRACT

Background: People with existing mental health conditions may be particularly vulnerable to the psychological effect of the COVID-19 pandemic. But their positive and negative appraisals, and coping behaviour could prevent or ameliorate future problems.

Objective: To explore the emotional experiences, thought processes and coping behaviours of people with existing mental health problems and carers living through the pandemic.

Methods: UK participants who identified as a mental health service user (N18), a carer (N5) or both (N8) participated in 30-minute semi-structured remote interviews (31 March 2020 to 9 April 2020). The interviews investigated the effects of social distancing and self-isolation on mental health and the ways in which people were coping. Data were analysed using a framework analysis. Three service user researchers charted data into a framework matrix (consisting of three broad categories: “emotional responses”, “thoughts” and “behaviours”) and then used an inductive process to capture other contextual themes.

Results: Common emotional responses were fear, sadness and anger but despite negative emotions and uncertainty appraisals, participants described efforts to cope and maintain their mental wellbeing. This emphasised an increased reliance on technology, which enabled social contact and occupational or leisure activities. Participants also spoke about the importance of continued and adapted mental health service provision, and the advantages and disadvantages associated with changes in their living environment, life schedule and social interactions.

Conclusion: This study builds on a growing number of qualitative accounts of how mental health service users and carers experienced and coped with extreme social distancing measures early in the COVID-19 pandemic. Rather than a state of helplessness this study contains a clear message of resourcefulness and resilience in the context of fear and uncertainty.

ARTICLE HISTORY

Received 3 November 2020
Revised 24 November 2020
Accepted 1 December 2020
Published online 22 January 2021

KEYWORDS



COVID-19; coping;
mental health

Introduction

On 23 March 2020, the UK government announced measures to manage the COVID-19 pandemic. People were told to remain at home, only go out for essential purposes, and to self-isolate if they came into contact with the virus or were in an “at-risk” group. Although these measures were introduced to protect the community and ease pressure on the UK NHS services, concerns have been raised about the consequences for mental health (Venkatesh & Edirappuli, 2020). Evidence from previous pandemics suggests an increased experience of difficult emotions such as anger, confusion and anxiety, and high prevalence of clinical disorders such as depression and post-traumatic stress disorder (PTSD) amongst those exposed to quarantining measures (Brooks, 2020). Estimates from late March to early April 2020, when this study was conducted, suggested that COVID-19 was affecting the well-being of 53.1% of the UK general population, with high anxiety reported by 49.6%

compared to 21% at the end of 2019 (Office for National Statistic, 2020a, 2020b).

There is, however, emerging evidence of improved mental well-being and reduced stress. These positive effects may be based on having more free time and reduced demands to leave home, but still being engaged in social interactions using technology (Lau, 2020; MQ & AMS, 2020). Individuals may also adapt to the stresses associated with the pandemic which is often referred to as resilience (Vinkers, 2020). Core psychological components of the “3 Cs” resilience model developed for natural disasters (Reich, 2006) include: Control (a feeling of personal agency), Coherence (managing uncertainty through knowledge provision by those in power) and Connectedness (feeling a sense of togetherness). In the USA going outside, exercise, a perception of strong social support, good sleep and spirituality are associated with stronger levels of resilience during the current pandemic (Killgore et al., 2020). Healthy family

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processes (e.g. good communication and shared beliefs) are also thought to promote resilience (Prime et al., 2020).

In the early stages of the UK lockdown, an online survey of people with lived experience of mental health problems highlighted concerns about the pandemic exacerbating pre-existing mental health issues (MQ & AMS, 2020). This is similar to previous pandemics. Anxiety during the 2009 H1N1 Swine Flu pandemic increased and individuals with pre-existing anxiety experienced more intolerance of uncertainty and fear of contamination (Taha et al., 2014; Wheaton et al., 2012). Informal carers may also be at risk of increased strain during the pandemic due to a reduced access to support services (Onwumere, 2020).

Mental health in those with pre-existing mental health problem is not inevitable as living circumstances and psychological factors also contribute and can mitigate people's experiences. Folkman and Lazarus' (Folkman & Lazarus, 1984) transactional model of stress and coping proposes that appraisals of both threat and coping influence how an individual responds to stressful situations. In relation to pandemics, beliefs about (a) how severe the virus is, (b) how effective the recommended behaviours are and (c) the individual's ability to engage in these behaviours, may be helpful in understanding changes in mental health (Teasdale et al., 2012). Support for this theory comes from data collected in the H1N1 Swine Flu (Prati et al., 2011) and SARS (Taha et al., 2014) pandemics as increases in anxiety and worry were mediated by appraisals of threat and control.

Exploring the psychological and individual factors that contribute to mental well-being or ill-health during the COVID-19 pandemic is a research priority (Holmes, 2020). This study investigated in detail the psychological experiences of people with mental health problems and informal carers in the context of the COVID-19 pandemic. We sought to elicit cognitive appraisals and behaviours that were either problematic for, or protective of mental health difficulties during a period of enforced social distancing.

Methods

Design

The study was based on principles of co-production with service user researchers being involved at all stages of the research process, including the generation of research questions, design, data collection and analysis. The qualitative methods involved semi-structured interviews.

Participant characteristics

Participants were eligible if they were at least 16 years and were either currently, or had experience of, using mental health services or they identified as an informal carer for somebody who has used services. Participants needed internet or phone access and were excluded if they were unable to give informed consent. They were recruited through purposive and snowball sampling via existing patient involvement and advisory groups.

Researcher characteristics

Six researchers conducted the interviews with participants. They all had lived experience of a mental health problems and the majority were employed as service user researchers. This experience allowed the researchers to relate more closely to the experience of participants being interviewed. Three service user researchers analysed the data, and, again, drew on personal experience to guide the interpretation.

Procedure and ethics

The study was granted ethical approval by the Psychiatry, Nursing and Midwifery Research Ethics Subcommittee at King's College London (reference: MOD-19/20-18180). Mental health service users and carers interested in research and who were members of advisory panels were approached and given an information sheet about the study by researchers at King's College London or a charity, the McPin Foundation, and given time to decide if they would like to take part in the study. Participants provided written informed consent which included an electronic signature via email prior to interview. The interviews were conducted by the six service user researchers between 31 March 2020 and 9 April 2020, via telephone or videoconferencing software, based on participant preference and accessibility. Clinical and demographic characteristics were collected and then participants were interviewed. They were reimbursed for their participation. Participants were provided with information on mental health support helplines and online resources and researchers also supported participants' well-being and welfare throughout the interview.

Interview

The topic guide was developed from research identifying the impact of past pandemics, social distancing and self-isolation on mental health, potential psychological mechanisms and coping strategies (available on request). The discussions explored: the general impact of social distancing and self-isolation on their mental health and access to services; specific triggers for mental health problems; current methods of coping; and other protective factors. The interviews lasted for approximately 30 minutes and were digitally recorded and transcribed using Microsoft Teams videoconferencing software.

Sample size and data analysis

We conducted interviews until data saturation was reached which was established by a review of the summary findings for each semi-structured interview question. A framework analysis (Gale et al., 2013) was applied to the data, combined with an inductive process to code themes that did not fit within the *a priori* framework matrix, consisting of three broad categories: "emotional responses", "thoughts" and "behaviours". Three service user researchers read and re-read transcripts and independently coded the data into

themes (created a summary label for individual quotes from each transcript), charting these themes into the framework matrix, i.e. whether the participant was referring to an emotion felt, a thought experienced or a behaviour engaged in. For data not categorised, each service user researcher generated a set of additional themes and they became major themes if they were coded by more than one person. The three service user researchers met on a regular basis to discuss and resolve discrepancies in their coding. However, a final set of major themes and subthemes were generated by one service user researcher (DM) who reviewed the three analysis results and amalgamated similar codes fitting inside and outside of the initial framework.

Results

Sample characteristics

Thirty-one participants were included in the analysis (21 women, eight men, two non-binary) and their ages varied from 16 to 79 ($M=42.61$, $SD 20.49$). More than half were service users (18/31; 58%), 16% (5/31) were carers and 26% (8/31) identified as both service users and carers.

Emerging themes

The summary of the full framework of themes is shown in Table 1 and these themes are described in detail below.

Emotional responses

Participants revealed a multitude of negative emotional responses to their current situation. These were categorised

into the seven themes, highlighted in bold, with illustrative quotes provided in Table 2.

Many participants expressed **fear**. This included fear of infection, fear of death, fear about the future and fear for their mental health^{1,1}. **Anger** was expressed as frustration^{1,2}, annoyance and irritability, e.g. losing their temper with others. Many felt a sense of **sadness** at their situation^{1,3} and commented about feeling “depressed”, “flat” and tearful. Some spoke of memories being reactivated and this producing negative emotions, including feelings of **guilt**^{1,4}. Others expressed **boredom** with things just feeling monotonous and tedious and every day being similar^{1,5}. Other negative feelings included participants expressing **disgust** at a lack of police presence or enforcement of social distancing measures^{1,6}. **Surprise**, and even horror, was expressed, for example, about racism and people not following recommending behaviours^{1,7}.

However, there were also more positive experiences (illustrative quotes also provided in Table 2). Some spoke of feeling of **happiness**^{1,8}, excited and experiencing a sense of relief for having “freedom” and less demands on their time. Others expressed a sense of **calm** and feeling more relaxed due to a slower pace of life^{1,9}.

Thoughts

These comments fell into five main categories of appraisals (see Table 2 for a list of illustrative quotes). Some appraisals directly related to **their life situation** with many describing difficulties with looking forward, disliking the novelty of the situation. They reported new sources of worry (e.g. about the effect on education, accessing essential items, and the wider societal, economic and political impact of the pandemic^{2,1}). Some reported having too much free time, which

Table 1. Framework of categories and emerging themes.

Framework category	Emerging themes	Service users ($n=18$)	Carers ($n=5$)	Both ($n=8$)
Emotional responses	Fear	13 (72%)	3 (60%)	6 (75%)
	Anger	11 (61%)	3 (60%)	5 (63%)
	Sadness	14 (78%)	3 (60%)	6 (75%)
	Boredom	5 (28%)	0 (0%)	2 (25%)
	Disgust	1 (6%)	0 (0%)	0 (0%)
	Guilt	4 (22%)	0 (0%)	4 (50%)
	Surprise	1 (6%)	0 (0%)	1 (13%)
	Happiness	4 (22%)	3 (60%)	2 (25%)
	Calm	4 (22%)	2 (40%)	3 (38%)
	Thoughts	Appraisals of their life situation	17 (94%)	5 (100%)
Appraisals of their relationships with others		16 (89%)	4 (80%)	8 (100%)
Appraisals of the virus		18 (100%)	5 (100%)	8 (100%)
Appraisals of organisations and services		18 (100%)	4 (80%)	8 (100%)
Appraisals of themselves		18 (100%)	5 (100%)	8 (100%)
Cognitive coping strategies		17 (94%)	5 (100%)	7 (88%)
Following recommended behaviours		17 (94%)	4 (80%)	8 (100%)
Behaviours	Health behaviours	18 (100%)	3 (60%)	8 (100%)
	Activities: leisure activities	15 (83%)	5 (100%)	6 (75%)
	Activities: home-focused activities	9 (50%)	3 (60%)	4 (50%)
	Activities: technology-related activities	17 (94%)	4 (80%)	8 (100%)
	Social behaviours	17 (94%)	5 (100%)	8 (100%)
	Approaches to the news	17 (94%)	4 (80%)	6 (75%)
	Religion and spirituality	1 (6%)	0 (0%)	2 (25%)
	Work and volunteering	4 (22%)	1 (20%)	5 (63%)
	Time management behaviours	16 (89%)	5 (100%)	8 (100%)
	Not much change	4 (22%)	1 (20%)	2 (25%)
	Other contextual categories	Being in a high-risk group	3 (17%)	1 (20%)
No change to life		14 (78%)	1 (20%)	3 (38%)

Table 2. Illustrative quotes for the participants interviewed for all dimensions and themes, referenced throughout the main text.

Dimension	Reference	Themes	Illustrative quotes
Emotional responses	1.1	Fear	"So on one hand I am glad the outside world has stopped for now, but on the other I am fearful of losing any sort of coping skills that I had." (MM1_female service user and carer)
	1.2	Anger	"It kind of makes you feel I suppose frustrated, that feeling like you're just trying to keep your days down, so you're almost, like, wasting time, waiting for it to pass – linking back to not having anything to make you feel productive. Like you feel like life's passing in a sense, you're just trying to sit it out, and not go anywhere for that time." (DM2_male carer)
	1.3	Sadness	"I feel like sometimes I do get worried about, like, I don't know maybe ... I'm not worried about it, but sometimes I just get really sad ... Uh, like, I'll just be on the – on the phone to my friend, to my, to my girlfriend or my friends and I'll just be like, I'm feeling quite sad right now, I'm not sure why." (CO5_male service user and carer)
	1.4	Guilt	"I'm trying to not feel guilty about anything that's not going well, you know, so I'm I'm struggling with doing my homework at the moment and I ended up missing the deadline because I was distracted reading the news, 'cause when all this coronavirus stuff happened, you want to know all you can about it. I spent like 10 days researching it all and just getting up to speed on it and sharing information with my family. Whereas what I should have been doing was my homework." (ELW7_female service user and carer)
	1.5	Boredom	"It's kind of like mind-numbing boredom. Like it doesn't end." (DM8_non-binary service user)
	1.6	Disgust	"I think I'd probably like to see a bit more of the police around, I suppose, just keeping an eye on people – you don't see, you still don't see very much of them, probably because there aren't enough of them. Nevertheless you, you, you see them around, but I haven't seen any any any police enforcing anything so far, which is a bit bit upsetting because there there have been times when I would have liked somebody to have been there to have actually said something and just tell them not to be so damn stupid." (DM7_male service user)
	1.7	Surprise	"I'm still quite horrified when you look at the stories of, you know, people sunbathing. I went last week – the end of the first week, I went to my local park and, uh, it was just like a normal day: groups of people sitting together, walking together, I was actually flabbergasted." (DM6_male service user)
	1.8	Happiness	"I feel quite happy. I mean I, I do quite enjoy my own company and stay in the house anyway so it's not. It's not a torture to me." (ELW4_male carer)
	1.9	Calm	"There's been a gradual slowdown, settling into a relaxing rhythm of being, sleeping, eating, exercise, hobbies, spring cleaning, gardening. Um, so it's been relaxing, it's been a relief in a way just to get off the treadmill of voluntary work and things that I do – my outdoor life." (CO3_females service user)
Thoughts	2.1	New sources of worry	"I was really frightened all time about a benefits etc of losing me benefit 'cause you know always continuous being accessed. And now I'm frightened all the hospitals appointment I have got are going to be shelved. And I am worried I'm just gonna be cut off and left with no income." (MM1_female service user and carer)
	2.2	Managing health better	"I'm resting a lot, so that helps my mood and, so yes, I'm looking after myself a bit more, instead of having an active life all the time." (DM4_female service user)
	2.3	Strained relationships	"I live with my sisters and my mom and my dad, and when I get frustrated I will get very short tempered. So being at home and being like, stuck, in like, this bubble sometimes gets me annoyed." (DM1_female service user)
	2.4	Others not following the rules	"Some people just don't follow the guidelines because they think they'll get away with it or it will never happen to them." (DM4_female service user).
	2.5	Worse than past viruses	"Initially I didn't feel the panic, and then it was only two they were putting in like procedures, like, social distancing, and more protective equipment and when they were talking about lockdown I thought 'OK yeah this is getting serious', and then when I started seeing people dying and it was going up and up and up each day and doubling and then we were on lockdown and I was actually thinking: 'right? This is definitely very serious and this is not just the flu. This is something more.'" (DM3_female service user and carer)
	2.6	No serious than past viruses	"I think it is very severe very. I think it's very serious. Um, because of how contagious it is, but I don't think it's any different from other, like SARS and swine flu and you know the general flu. It's more contagious than that, but I I personally don't. I I think it's been blown blown up too much uhm, even though it is very, very serious and a lot of people are dying." (SS2_female service user)
	2.7	Challenge of determining accurate information	"Um, I think I've, you know, I've-I've seen there's always, so very sensationalistic, um reporting in the media. You know, including from newspapers you know that both – both, you know, strike both, you know in terms of overhyping the risk and also underestimating the risk. I mean, I'm – I'm lucky because I can, you know, I know where to look. You know the BMJ have, you know, you know, are doing a really good range of features on-on the Coronavirus and COVID-19, so I know-I know where I can find reliable sources of information." (CO1_female service user)
	2.8	Response of services; inequalities	"I think that this is especially hard on people from minority communities right now. We don't have equal access to healthcare anyway as it is. We're not believed as often as it is or our symptoms aren't taken seriously, seriously enough as it is on a general scale so it's a scary time." (JE3_trans male service user and carer)
	2.9	Services are doing their best	"Most, from what I've experienced, most mental health services are doing a really great job. And, uh, they're going above and beyond. Particularly the NHS ones, and particularly [NHS Foundation Trust], which is the one that I'm affiliated with. So like I know, as a patient of theirs. I get loads of support through social media. When I say social media, Twitter uhm. And like. Yeah, they're coming up with sort of new strategies and or just need papers,

(continued)

Table 2. Continued.

Dimension	Reference	Themes	Illustrative quotes
			new articles, publishing new research, and that's all really helpful to me." (SS2_female service user)
	2.10	Resilience	"I don't think you can generalise, but sort of making the comparison with other, um, traumatic situations and if you put into context it's actually not that bad. And I wonder if, because I've heard it from other service users as well, if it helps us cope with the situation, at least in the short-term because we have encountered similar or worse before. Compared to other people who may have never encountered any periods of adversity in their lives." (CO2_female service user)
	2.11	Acceptance	"I haven't had any episodes where I've been having panic attacks or very stressful ... but I think it's because I've kind of adapted to, like 'this is how it is so far, and there's nothing I can kind of do about it other than just relax.'" (DM3_female service user and carer)
	2.12	Collectivism	"the weirdest thing about all of this is that we are all in a kinda levelling position. You know this is, this level of anxiety is what most of us service users go through all the time ... between different nations, between different religions. Professionals and service users, you name it. We are all the same at the moment. In a way that is comforting." (ELW7_female service user and carer)
	2.13	Determination	"I think we're in this for the long haul, in which case I ain't got no choice but to somehow get through it, which kind of describes how I feel about my voices anyway – I've had no choice, but I have to keep going and so I think with the current situation, well this is where I am, I have no choice." (DM6_male service user)
	2.14	Optimism	"I'm an optimist. I always try and look on the bright side, which is sometimes challenging. Er, so I'm not sitting here panicking." (DM6_male service user)
	2.15	Pragmatism/stoicism	"you sort of just change gear somehow. I mean, you know, you don't go out, you can't socialise and ask other people and chat with other people. So you change gear and get on with it by yourself really more than you would have previously. If that makes sense." (CO3_female service user)
	2.16	Scepticism	"I have a science background so I draw my own – I do my own research and I don't buy into the fearmongering or whatever it might be on any given day. You know. So – I'm not easily influenced by social media." (CO2_female service user)
	2.17	Self-compassion	"I'm trying to not feel guilty about anything that's not going well, you know, so I'm, I'm struggling with doing my homework at the moment and I ended up missing the deadline because I was distracted reading the news." (ELW7_female service user and carer)
	2.18	Remembering the past	"I had a happy childhood, normal childhood, so that is a well of, um, well-being for me. I can always go back to knowing the good times in the past when I was young and-and that is a great reserve to draw on because I knew, you know, I was happy then and all was well and safe. So that helps – if you have a good frame of mind it helps you get through tough times yeah, yeah." (CO3_female service user)
	2.19	Living in the present	"I'm trying to take one day at a time. Like I'm not looking very far ahead. I'm just trying to keep my health tiptop, um, practice mindfulness and um, no I don't look very far ahead. I know it could well be a long drawn out thing and it could get much worse, but I can't go there. I don't go there." (CO3_female service user)
	2.20	Imagining the future	"I'm missing some activities that I went to before, like going to church, but at the same time I'm kind of I don't know ... I don't think our government in lockdown for very long so, I know that I, I expect that I will have the option go to church in about a month." (ELW7_female service user and carer)
	2.21	Mental distraction	"I guess I'm just trying to distract myself with other stuff instead of, you know, just thinking, like, I don't really want to think about myself, I actually wanna get my mind to do like something else interesting, to distract myself." (ELW6_female service user)
	2.22	Psychological distancing/detachment	"And the one thing I tried, I tried to, to a certain extent if things aren't going to that well I try and step away and think well it's not going well here, but I'm not gonna get dragged in and get upset. I'm good. I detach myself from it." (ELW4_male carer)
	2.23	Finding rules to abide by	"I'm someone who likes rules. It gives me a sense of security of some sort. Then I know what I'm supposed to be doing." (CO2_female service user)
	2.24	Self-reflection and insight	"I very much tend to reflect, and if I think, well it's really not working here and the input I'm giving isn't necessarily working, I'm going to step back. Uh, that that's what that's what I've been kind of thinking about a lot, and reflecting." (ELW4_male carer)
	2.25	Managing expectations	"they [my coping mechanisms] are going to have to be very very good. You know, it's never gonna be as good as what it was before, because I could go out, I could see people, I could talk to people, and spend time with other people. But this is just about getting through. It's not gonna be as good, but it's got to be good enough." (DM6_male service user)
	2.26	Perspective taking	"I understand that it-it's a very contagious disease and people are in their thousands obviously are dying from it, but I try to put it into some sort of perspective that there are also thousands of people that don't get it. And there are also thousands of people that get it and recover, and have it very mildly." (CO4_female service user)
Behaviours	3.1	Precautionary behaviours: handwashing, gloves	"we go to the shop probably every other day – our local shop. Both my partner and I, and we put on gloves when we go. We wash things down when we get home, we wash our hands, um, so that is the only contact we have with people, is going to the shops." (CO4_female service user)
	3.2	Challenging eating behaviours	"I have an eating disorder so it's quite difficult to be at home a lot just with food around and starting to have some of those like difficult thoughts and trying to keep restricting behaviours from happening again. And also the like mass panic buying so even if I do need to go and buy foods then I'm limited in what I can buy, which causes me even more

(continued)

Table 2. Continued.

Dimension	Reference	Themes	Illustrative quotes
	3.3	Disrupted activities	anxiety because I buy the same things and I like to know that I'm buying the same things. So when I have to change that, it's really stressful." (JE3_trans male service user and carer) "So my coping strategies: I mean one, I'd been going to the gym the last couple years and found that that's quite important in terms of, you know, just trying to maintain my energy levels because so much emotional mental energy goes into just dealing with the voices and I have sleep problems as well ... One of the other things I do is listen to music a lot and play the guitar. And I was going to place called [NAME], which is an Art Centre for people with mental health problems. And they have a guitar group every Wednesday afternoon, and I would go to that and I'd play guitar with other people, so I lost that. ... I'm [also] an amateur photographer, and I would go out and take pictures sometimes, probably not as much as I should, 'cause most of the time I'm too tired, but I used to enjoy doing that as well ... So all of that has just gone out the window." (DM6_Male service user)
	3.4	Keeping busy doing household chores	"I tidied up my room because I felt like if I tidy my room and my environment is clean, that I'm in, it makes me feel better." (DM3_female service user and carer)
	3.5	Mobile apps	"I've started using this wellbeing app called Thrive. Um, normally it's something like a doctor would refer you to but I was googling wellbeing apps and found it so I just contacted them and they gave me a login ID. So I started using that and that just kind of teaches you a bit about CBT and then it has like other relaxation techniques, activities and things like that. So even as something to pass the time." (DM5_female service user)
	3.6	Having personal space; good communication at home	"in the family, we are, we're, we're generally a close family but obviously we have lots of arguments but we're coping quite well with keeping that separate. We hardly manage to go out on a week's holiday without arguing, we haven't had a proper argument since this started. I think yeah, we're just learning to like keep each other, like keep our distance. Like we all have things that we're doing, like my dad's doing a lot of work, my mum's kind of a bit ill so she's not doing as much, my sister spending all her time face timing her friends and so we're also sort of keeping separate which helps. And then we've set up a bit of a rota for the chores and like cooking dinner and washing up and stuff which is helping, yeah." (JE1_female service user)
	3.7	Religion and spirituality	"I'm still involved in a prayer group, uh, which is something that I've been involved in for about a year. So that's now meeting online and before you know, we met in someone's house before, so that's nice 'cause it still gives me that feeling of being a part of the group." (ELW7_female service user and carer)
	3.8	Work	"it's a big deal because my work is a big way – is a big part of me, you know, feeling connected and feeling I have purpose in my life." (CO1_female service user)
	3.9	Change in routine	"I think, one doesn't appreciate just how reliant you are on routines until you can't do them anymore, and then you realize that actually they're there and all the time they were there and you didn't really realize. So yes, you have to replace those, yes." (DM7_male service user)
	3.10	Taking things day by day	"I'm just, you know, focusing on where I am at this moment in time, then everything is kind of OK. I don't know how long lockdown will go on." (ELW7_female service user and carer)
	3.11	Limiting news consumption	"I want to keep up to date but I don't, um, it distresses me to hear all the 'what ifs' and all the prognoses and you know it's all in the future, isn't it? Nobody really knows." (CO3_female service user)
	3.12	Not much change	"Well, I used to be quite isolated, so I'm not one of these people who is close to people around people joining in things with groups of people. So, in that respect, it's not something that I used to, so I don't. You know, it's it's not difficult for me in that respect." (MM1_female service user and carer)
Other contextual information	4.1	High risk groups; additional strain of being a carer	"because I'm a carer and my daughter relies on me to some extent, emotionally, particularly not practically so much, but the thought of me not being here suddenly, you know, would be quite distressing. So that is a that is quite a big worry for older carers, I'd say." (SS4_female service user and carer)
	4.2	No change	"I guess it doesn't-doesn't make much of a difference to me like I said earlier, which is strange. I guess for some people they were worried, I mean, my care-coordinator or whoever, I think they were worried it would exacerbate my OCD symptoms like exponentially. But I think gosh, it's hard to generalise, but I think to some extent I'm less worried than other people maybe because to me it's second nature. You know I'm so used to avoid touching anything and being very, very aware of what I touch. You know, if I touch my – or when I wash my hands before eating or touching my face or whatever, so I kind of trust my own routine in that sense." (CO2_female service user)

made worries harder to contain. More positive appraisals on life circumstances included thoughts about increased time to manage their health condition^{2,2}. Not feeling stuck indoors and having some freedom, e.g. to go for a walk, were also viewed as positive.

There was a strong message that social support was vital. But many reported a strain on **their relationships** in the home because of the pandemic^{2,3}. Some expressed negative

views about the behaviour of others (e.g. not following rules^{2,4}) and felt divide between "healthy" and "vulnerable" groups and were concerned about who would receive healthcare resources (e.g. ventilators).

Some spoke of **the virus** as highly contagious, very serious and worse than past viruses, with a risk of death^{2,5}. Consequently, they were very worried about catching the virus and the stigma attached to those who might have

contracted it. But others thought COVID-19 was no more serious than past viruses and felt safe as they were unlikely to come into contact with it^{2,6}. Participants felt there was a challenge in determining the accuracy of information provided about the pandemic^{2,7} and some spoke of rumours or conspiracy theories that they had heard. Coverage in the media was perceived as negative and scary, revealing the damage outside the relative security of their own homes. Some felt that this coverage was overly negative and not presented a balanced overview of the current risk.

Some participants expressed dissatisfaction with **organisations and services**. For example, in terms of the government's response; they felt it had been slow, recommended ineffective behaviours, and lacked enforcement or helpful information. They worried about the pressures on health-care, and were concerned about the cancellation, postponement or adaptation of their care. Remote support was valued but, for a few, it was not viewed as the same as in-person care. Some felt their health issues were treated as secondary to COVID-19^{2,8}, whilst others, mindful of the high demand faced by the NHS, felt unable to reach out for help. They expressed several unmet needs (including the need for increased service provision and improved communication) and a sense of hopelessness that services would not improve during the crisis. Other participants, who were receiving support, thought mental health services were doing their best or even doing well, and were important for keeping them well^{2,9}. They spoke of trusting officials and professionals but suggested that services needed to increase their visibility to the public about being open (e.g. through using social media to broadcast this message).

In addition to the appraisals of their environment and the world around them, participants also expressed thoughts about **themselves**. Negative attitudes towards oneself were common and exacerbated by the pandemic, with participants thinking that they were being judged and had low

self-worth. Some also expressed feeling isolated and lonely. The majority felt uncertain and some spoke of thoughts about feeling lost, unmotivated and overwhelmed. They worried about their ability to cope long term but not all appraisals of self were negative. Many felt that they were more resilient because they had learnt coping strategies from past adversity that they could draw on and felt better prepared to manage a crisis^{2,10}. Participants acknowledged the importance of feeling safe and a sense of control during times of great uncertainty and making adjustments in their daily routine provided that sense of autonomy and ownership. Participants expressed several **cognitive coping strategies** that were helping them to manage the current situation. These ways of coping are summarised in Figure 1.

Behaviours

Eight main themes emerged (see Table 2 for selected quotes from participants). In terms of actions directly related to the virus, participants followed the **recommended behaviours**, e.g. rules around social distancing, but sometimes this was more difficult, for practical and emotional reasons. Other precautions were followed including staying at home as much as possible, the use of gloves and masks, increased handwashing, and sanitising objects^{3,1}. Some illness-related behaviours were reinforced by the current situation, e.g. excessive handwashing and checking (the news) for individuals with obsessive compulsive disorder, and preoccupation with access to the right foods and reduced exercise for those with eating disorders^{3,2}. More generally, in terms of **health-related behaviours**, participants spoke of disrupted sleep and exercise routines as well as missing medication. Despite these difficulties, many spoke about actions to maintain good health (including mental health), such as taking medication as prescribed, monitoring for symptoms of COVID-19, maintaining good levels of hygiene, supporting the

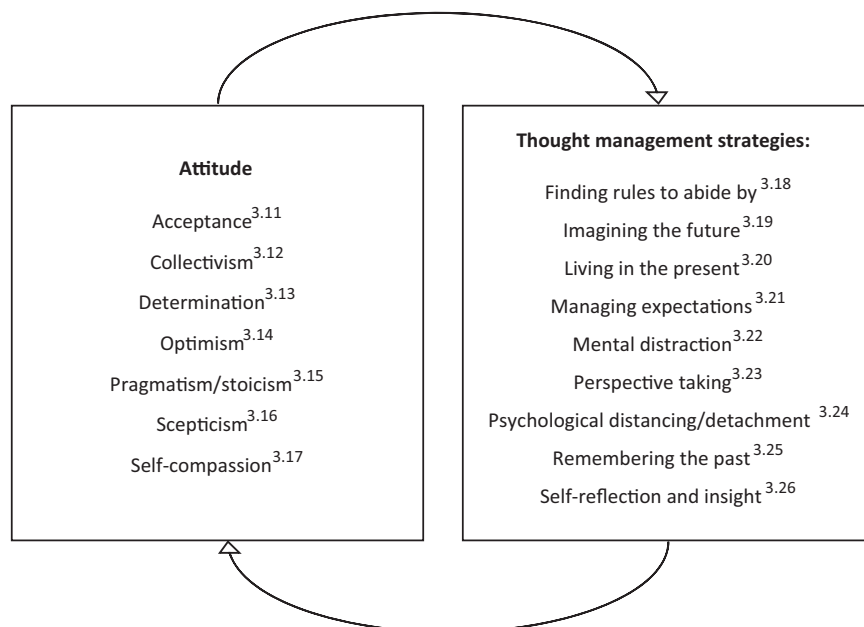


Figure 1. Examples of thoughts as coping strategies.

immune system with vitamins, eating well and exercising (including walks).

Participants spoke about how they were spending their time and the changes associated with this. Many **leisure activities** had been disrupted or stopped altogether^{3,3}. Despite this, participants discussed activities they were enjoying. Participants specifically spoke about **home-focused activities**, taking the opportunity to do more gardening, home improvement and household chores^{4,4}. Some concerns were raised about excess use of computers, smartphones and televisions but participants viewed **technology-related activities** as very important to enable socialising and to support leisure activities (e.g. listening to podcasts, watching television and films) and health management (e.g. use of mobile health apps^{3,5}). Maintaining **social behaviours** and support through virtual means was reported as important due to less physical contact but so was the maintenance of personal space^{3,6}. Good communication, and sometimes humour, was considered vital when interacting with others. Some reported continued engagement in organised online prayer groups and virtual services^{3,7}. Others engaged in more personal forms of **religious worship and spirituality**. In addition, continued engagement in work was a way of remaining occupied and provided a sense of purpose^{3,8}. Where paid **employment** was limited, participants spoke of engagement in volunteering, e.g. research and patient and public involvement (PPI) opportunities.

Change in routine was a common experience with the need to adapt to a new way of living^{3,9} and **manage their time differently**. Establishing and maintaining a new routine was described as a positive way of coping and feeling in control. Although some felt that they were being less productive, others described keeping busy and distracted. Rather than planning for the future, participants described taking things day by day^{3,10}. Many wanted to keep informed about COVID-19 for some sense of control, but they also raised the importance of limiting **news consumption** as it was distressing^{3,11}.

Despite changing their current behaviour, some felt that life was not much different, especially those who were socially isolated before the pandemic^{3,12}.

Other contextual categories

It may be important to note that a minority of participants had concerns about **being in a high-risk group** (e.g. an older adult, a person with a pre-existing physical health condition or being a keyworker in addition to being a service user and or an informal carer). Participants belonging to these high-risk groups (including carers in the sample) spoke about being severely affected by the restrictions and feeling greater levels of distress^{4,1}. Some participants did not experience their life circumstances as either positive or negative or reported **no change** and some reported a continued low level of social interaction or cleanliness, through choice, rather than following any recommendations^{4,2}.

Comparing the views of service users and carers

Service users and carers expressed their own unique challenges. For service users, pre-existing health conditions, obtaining medication and re-emerging symptoms of mental health conditions were the main concern, whereas for carers it was their additional responsibilities for others that was causing potential pressure and strain. Formal support was discussed by service users more than carers.

Although service users spoke more about the challenges related to following the recommended behaviours, a greater proportion of service users reported that they were self-isolating. They expressed feeling less physically connected to others, which was associated with a variety of negative emotions, including stress or anxiety and anger, and feelings of exclusion or longing for social contact or boredom. Carers reported negative emotions but only fear, anger and sadness. Service users discussed disruption to the structure and routine of their life more than carers and more concerns were raised about their ability to sustain coping, long-term. Despite the negative experience described, service users spoke proportionally more about feeling safe, in control and grateful and fortunate relative to others.

The personal accounts suggest that service users and carers may also have coped slightly differently during the pandemic. Service users spoke about turning to technology, e.g. for social interaction and support, more than carers, who talked about being busy and distracted in other ways (including caring tasks). Whilst service users and carers both expressed interest in keeping informed about the pandemic, service users spoke more about limiting news consumption because it was affecting their mood negatively.

Discussion

This study builds on a growing number of qualitative accounts of how mental health service users and carers experienced and coped with extreme social distancing measures early in the COVID-19 pandemic. Our findings provide a formulation, structured through a simple framework. Despite its simplicity, the richness and varied nature of the accounts was apparent.

Whilst some experiences replicated previous findings, especially the experience of negative emotions and an exacerbation of mental health symptoms (Brooks, 2020; Gao et al., 2020; Huang & Zhao, 2020), people in this study also spoke about resilience and positive experiences of adaptation and coping. The quality of the emotional reactions varied across individuals but this contributes to a growing literature suggesting that people experience a multitude of different negative emotions in response to pandemics and social distancing measures including, confusion, fear, anger, grief, boredom and frustration (for a review, see Brooks, 2020). However, it also suggests that people can have positive experiences of lockdown including, an increased sense of freedom, joy and calmness due to increased leisure time and the slowed pace of life. With people being encouraged to work from home and some furloughed, leisure time increased and there was greater opportunity for family time,

which may have led to improved wellbeing. A qualitative study conducted in care-givers of patients with COVID-19 highlighted that positive and negative emotions often co-exist, but that negative emotions are dominant during the early stages of the outbreak and positive emotions appear much more gradually, which coincided with psychological or life adjustment (i.e. diary writing, mindfulness, exercise, distraction, humour and rationalisation) and growth (i.e. gratitude, personal development and self-reflection) (Sun et al., 2020). Given that the response to COVID-19 and associated restrictive measures appears to be heterogeneous, future research should endeavour to elucidate the factors that determine whether a person is able to adapt and cope with the challenges that the virus presents and whether lockdown has a negative or positive impact on their mental health. Moreover, it will be important to determine which factors, if any, are protective of wellbeing.

In our study, participants spoke about resilience, adaptation and coping. In a recent qualitative study that examined the impact of COVID-19 on mental health service users, hospital and care staff expressed hope that an increase in resilience in mental health service users would be one positive outcome from the pandemic (Johnson et al., 2020). So far, preliminary evidence suggests that psychological flexibility and resilience are associated with greater well-being during lockdown (Dawson & Golijani-Moghaddam, 2020; Killgore et al., 2020). Folkman and Lazarus's theory (Folkman & Lazarus, 1984) proposes that experiences of stress are first influenced by primary appraisals (of threat) and secondary appraisals (of coping resources), then by the ability to implement cognitive and behavioural responses (coping strategies). In our interviews, some people felt threat in relation to the virus (the primary appraisal) and some did not, but it was clearly felt to be an uncertain and disruptive time, generating fear about the future, especially for service users. The role of uncertainty in distress has been documented in relation to previous pandemics (Taha et al., 2014) but the level of disruption caused by population-wide social distancing measures associated with the management of the COVID-19 pandemic may be unique. In terms of the secondary appraisal, perceptions of coping resources, these were influenced by their service user or carer status with people expressing confidence arising from past experiences of adversity and support from mental health services. Resilience may, in part, arise from knowing how to respond to challenges and feeling in control (Reich, 2006). Where people felt out of control and unable to cope, they expressed more stress. Of note, was the increased reliance on technology, especially for service users, which, in the face of social distancing measures, enabled continued contact with others and the ability to maintain purposeful activity, e.g. employment.

Strengths and limitations

This work is unique in that it was designed and run by service user researchers. The benefits of user-led research have been described in Ennis and Wykes (2013) and include

greater ease of recruiting to targets and the ability to empathise more closely with the experience of those being interviewed. All recruitment and data collection were performed remotely, encouraging the participation of those who were hard to reach and providing convenience and flexibility (Janghorban et al., 2014), but required participants to have access to technology and may not generalise to people who do not have the same access. Whilst we are unable to draw any causal inferences from qualitative data, the results serve as a basis for larger quantitative studies that will help to measure, and test hypotheses generated through the eyes of service users. Data for this study were gathered during a specific two-week period during the UK lockdown, this may have significantly influenced the results generated. Further research in this area should take a longitudinal rather than a cross-sectional approach, factoring in the influence of time. The influence of factors such as age, ethnicity, gender and location may also be important. In this study, the majority were middle-aged, women, who self-identified as a mental health service user or carer and this may have influenced the results. For example, Orgeta and Health (2009) and John and Gross (2004) found that older adults were better able to regulate emotions, had better coping strategies and used cognitive reappraisal techniques more often.

Conclusion

In this study, we took a practical approach, using opportunistic sampling methods, to gain a better understanding of how carers as well as mental health service users were coping, not just focusing on poor mental health but also on protective factors. The aim was to describe the psychological experiences of people who may be vulnerable to distress following the COVID-19 outbreak and enforced social distancing measures. Service users and carers may have their own unique challenges and solutions, but, both groups, emphasised factors that maintain wellbeing. The specific ways in which people coped at the beginning of the UK lockdown period may serve to inform recommendations for management of mental health during pandemics.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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