

1 **Exploring the recovery journey of COVID-19 critical care survivors during the**
2 **first year after hospital discharge**

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20 **ABSTRACT**

21 **Objectives:** To explore the longitudinal recovery of patients admitted to critical care
22 following COVID-19 over the year following hospital discharge. To understand the
23 important aspects of the patients' recovery process and key elements of their
24 caregivers' experiences during this time.

25 **Design:** A longitudinal qualitative study using semi-structured interviews.

26 **Setting:** Two acute hospitals in South East England and follow-up in the community.

1 **Participants:** Six COVID-19 critical care survivors from the first wave of the pandemic
2 (March-May 2020) and five relatives were interviewed three months after hospital
3 discharge. The same six survivors and one relative were interviewed again at one year.
4 Interviews were transcribed verbatim, anonymised, and a reflexive thematic analysis
5 was conducted.

6 **Results:** Three themes were developed: (1) “The cycle of guilt, fear and stigma”; (2)
7 “Facing the uncertainties of recovery”; and (3) “Coping with lingering symptoms – the
8 new norm”. The first theme highlights survivors’ reluctance to share their experiences
9 associated with contracting the disease. The second theme, explores challenges
10 faced by the survivors and their relatives in navigating the recovery process, given the
11 unknown nature of the illness. The final theme illustrates the mechanisms survivors
12 develop to come to terms with the remnants of their illness and critical care stay.

13 **Conclusions:** The longitudinal nature of the study highlighted the persisting
14 symptoms of long COVID-19, their impact on survivors and coping methods amidst
15 the ongoing pandemic. Further research into the experiences of those affected in the
16 first and subsequent waves of the COVID-19 pandemic, is desirable to help guide the
17 formulation of the optimally supported recovery pathways.

18

1 INTRODUCTION

2 Background

3 Since the coronavirus-19 (COVID-19) pandemic began in March 2020, the UK has
4 registered over 23 million cases. More than 900,000 required hospital admission.
5 Between February to August 2020, 10,953 patients were admitted to intensive care
6 units across the country [1], 71.9% of those patients received advanced respiratory
7 support, which often left survivors with complex physical and mental health problems
8 after discharge.

9 Post-intensive care syndrome (PICS) is a set of physical, psychological, and cognitive
10 symptoms which affect the survivors after discharge from critical care [2, 3]. Admission
11 to an intensive care unit (ICU) has also been shown to affect the patients' families,
12 resulting in psychological sequelae including depression and anxiety [4–7].
13 Additionally, COVID-19 itself has left many patients with post-viral illness symptoms,
14 [8–11], some of which have been shown to persist up to a year after hospital discharge
15 [12]. The term 'Long COVID' or 'post-COVID syndrome' has been used to describe
16 this long-haul illness [10,11,13–15]. The symptoms of PICS and Long COVID can
17 overlap, as both conditions cause physical, psychological and cognitive symptoms.
18 While it is important to evaluate each patient individually to determine their symptoms,
19 both PICS and Long COVID have been described to have long-term impact in patients'
20 lives. It is possible that COVID-19 survivors who have had long ICU stays may suffer
21 from both of these long-term conditions (PICS and Long COVID) and may have
22 additional long-term health care needs.

23 Qualitative studies allow for in-depth understanding of complex conditions [16], such
24 as PICS and Long COVID. Both qualitative and quantitative studies have explored the
25 impact of ICU admission on COVID-19 survivors and their relatives in the first wave of
26 the pandemic [17,18]. The recovery pathway from the perspectives of both
27 stakeholders has been the focus of several studies [9,12,18–20]. However, to our
28 knowledge, no previous qualitative studies have explored the recovery needs of
29 survivors and their families over time. To formulate the optimal rehabilitation process
30 for patients with Long COVID and/or PICS and their families (PICS-F), the experiences
31 of both stakeholders over time, need to be explored.

1 The recovery pathway was significantly altered during the first wave of the COVID-19
2 pandemic due to strain put on health and social services, social distancing and
3 uncertainty associated with this new disease [17]. A case study investigating the role
4 of recovery clinics for a COVID-19 critical care survivor, found increased need for
5 extensive follow-up [19]. A systematic review studied interventions in PICS-F, found
6 clear communication and information sharing vital to treatment of the families [4].
7 While these studies provide some insight into the areas for improvement in post-
8 discharge recovery, the optimal recovery pathway, considering the long term needs to
9 patients and families is yet to be clearly defined. Moreover, these findings need to be
10 put in the context of the COVID-19 pandemic, taking into consideration the challenges
11 it posed to healthcare professionals, as well as survivors and their relatives. To date,
12 little is known of the long-term experiences of recovery following critical illness due to
13 COVID-19, limiting our understanding of the care needs of patients and families which
14 is essential in designing suitable care pathways. **In addition, lessons from patients and
15 relatives' experiences during the pandemic and should be learnt, in order to improve
16 patient care in the future.**

17 **Aims**

18 The present study aimed to explore the longitudinal progression of patients admitted
19 to ICU following COVID-19 illness and their relatives over one-year follow-up after
20 discharge from critical care in the first wave of the COVID-19 pandemic; to gain a
21 better understanding of their recovery process and their care needs over time, as well
22 as to explore the key elements of the caregivers' experiences during the recovery
23 period.

24 **MATERIALS AND METHODS**

25 **Design**

26 A longitudinal qualitative study using semi-structured interviews. A Consolidated
27 Criteria for the Reporting of Qualitative Research (COREQ) checklist for this paper
28 can be found in appendix 1.

29 **Sampling and recruitment**

30 Six COVID-19 critical care survivors from the first wave of the pandemic (May 2020 to
31 July 2020) and five of their relatives were recruited. Participants were approached face

1 to face, while in hospital by the research team and invited to take part. This was
2 followed up by a telephone invite after discharge from hospital. Informed consent was
3 gained again immediately prior to the interview. In-depth qualitative interviews
4 exploring their experiences of critical illness and recovery needs were conducted at
5 three months post-hospitalisation [22]. The same six survivors and one of the relatives
6 were subsequently interviewed again one year later. **Reasons for loss of follow up of
7 the four remaining relatives were not recorded.** Sampling was not determined by
8 saturation. Instead, a maximum variation strategy [23] was applied aiming to recruit
9 participants with a range of characteristics including age (younger than 55 and older
10 than 65), mode of ventilation (endotracheal tube, tracheostomy, and Continuous
11 Positive Airway Pressure) and length of hospital stay (**less than 10 days and more
12 than 20 days**) [24]. The relatives were recruited using a snowball strategy [23],
13 whereby the survivors were asked to invite the relatives or friends who have been
14 involved in their recovery; the participants could decide whether the interviews would
15 be conducted together or separately. Reaching a rich data set guided the choice of
16 sample size, with a variety in participant demographic traits and their experiences
17 during hospitalisation. **All participants included in the first round of interviewing (at 3
18 months post admission) were invited to be interviewed again at one year. No new
19 participants were recruited at the one-year follow up point.**

20 **Interview procedures**

21 Semi-structured interviews were conducted following a topic guide by ACG and AH.
22 Both co-authors, are female, and were physiotherapists and researchers at the time
23 of data collection, without having any previous contact with the study participants. Both
24 interviewers had relevant training in conducting qualitative interviews. ACG had led
25 qualitative studies in the past. Study participants were made aware of the aims of the
26 study and knew the interviewers were physiotherapists. The topic guide covered the
27 participants' experience of illness due to COVID-19 and probed their narratives of
28 going through or supporting recovery and rehabilitation post-admission to critical care.
29 Additional topics of discussion were added during the interviews at one year to follow
30 up topics mentioned by survivors at three months. An example of an interview topic
31 guide from 12 months interviews is available in appendix 2.

1 Two dyads (survivor-relative) were interviewed together at three months; one dyad
2 was interviewed at one year. All other participants were interviewed on a one-to-one
3 basis by telephone or videocall. Interviews lasted on average 57 minutes at three
4 months and 38 minutes at one year.

5 **Analysis**

6 All qualitative interviews were audio recorded, transcribed verbatim and analysed
7 following principles of Reflexive Thematic Analysis [25]. Only “audio data” was
8 collected and analysed from the interviews conducted by videocall. NVivo (Release
9 1.4.1, QSR International, Pty Ltd) was used to aid data organisation. The six steps of
10 data analysis as described by Braun & Clarke[16] were followed. Reflective logs were
11 kept to report on possible assumptions as well as initial aspects of interest triggered
12 by this initial exposure to the data. All transcripts were initially coded by two of the
13 authors (LW & ACG). These were inductive or data driven codes, initially very close to
14 the participants own words. A subset of transcripts was also read and coded by the
15 other two members of the research team and then discussed. These discussions took
16 place to promote “thinking aloud” and stimulate more in-depth interpretations of the
17 data. After these discussions, more latent codes were generated. The whole data set
18 was then re-read and recoded with more latent codes by LW. Codes were then
19 compared and discussed by the research team and supported using a reflective diary
20 and constant references back to the original data set, in order to work towards the
21 generation of the final themes. After several iterations of writing, discussions within the
22 research team, the analysis was refined. The following steps were taken to ensure
23 trustworthiness of the analysis. The use of an interview guide, the thick description of
24 the data, and the triangulation of codes with multiple members of the team ensured
25 the credibility of the findings [24].

26 **Ethical approval**

27 The present study received ethical approval from the UK Health Research Authority
28 approvals (Yorkshire & The Humber - Bradford Leeds Research Ethics Committee,
29 20/YH/0157, IRAS 280041). Formal oral consent (audio recorded) was obtained from
30 all participants.

31 **RESULTS**

1 Sample characterisation

2 A total of 11 participants (six survivors, five relatives), across two different acute
 3 hospitals were interviewed at three months after discharge. At one year, the same six
 4 survivors were interviewed, alongside one relative. Four out of the six survivors were
 5 male, whereas all five relatives were female. The average age of survivors was 65
 6 years and 59 years for the relatives. The average number of days in ICU was 14 and
 7 the average number of days in the hospital was 23. Further detail on the sample
 8 characterisation can be found in table 1.

9 *Table 1- Sample characteristics*

Survivors (n=6), interviewed at 3- and 12-months post discharge	n (%) or mean (range)
Age range at first interview (years)	65 (54-74)
Gender (male)	4 (67%)
Length of stay in ICU (days)	14 (8-36)
Hospital length of stay (days)	23 (13-44)
Ventilation mode	
Endotracheal tube only	2 (33%)
Continuous Positive Airway Pressure only	1 (16%)
Combination of Endotracheal tube and Continuous Airway Pressure	2 (33%)
Combination of Endotracheal tube, Continuous Airway Pressure and tracheostomy	1 (16%)
Carers (n=5 initial interview at 3 months; n=1 follow up interview at 12 months)	n (%) or mean (range)
Age range at first interview (years)	59 (50-70)
Gender (male)	0 (0%)
Relationship to survivor	
Spouse or partner (n=1 on follow up)	3 (60%)
Adult child	1 (20%)
Close friend	1 (20%)

10

11 Main results

1 Three themes were developed to explore the journey of the patients and their relatives
 2 one year after stay in ICU with COVID-19. The first theme, “The cycle of guilt, fear and
 3 stigma” investigates the complex feelings associated with contracting and surviving
 4 COVID-19. The second theme, “Facing the uncertainties of recovery” gives insight into
 5 the frustrations survivors and their relatives faced with severe, long-standing illness,
 6 and the support they reached out for during recovery. The final theme, “Coping with
 7 lingering symptoms – the new norm” analyses the mechanisms survivors developed
 8 to come to terms with the remnants of their illness and critical care stay. Figure 1
 9 illustrates these three themes and the longitudinal nature of our analysis.

10 **Theme one: The cycle of guilt, fear and stigma**

11 The first theme explores the outlook of the survivors on having contracted COVID-19,
 12 the guilt, fear and stigma of having been ill and the resulting reluctance to share their
 13 experiences.

14 *‘there was... there seemed to be a fear of admitting that you had COVID because*
 15 *people might shun you.’ (relative, age 70, 12 months follow-up)*

16 *“If we're meeting anybody new, (...) [my husband] feels he has to tell people that I*
 17 *had COVID. And I don't.” (survivor, age 74, 12 months follow-up).*

18 There was a noticeable contrast between the reluctance of the survivors and the
 19 honesty of their relatives when talking about their memories of COVID-19. Survivors’
 20 experience of hospitalisation was different for them and their caretakers – while the
 21 former do not remember the events during the days they were on a ventilator, their
 22 relatives have very vivid memories of the stress, fear and resulting trauma brought on
 23 by the worry for their loved ones. Thus, one of the reasons for the survivors’ reluctance
 24 to share their experience may be the guilt for causing their relatives’ distress.

25 *“When I came out of hospital, both my wife and I have been both down so many times,*
 26 *especially when you are seeing it on the TV and actually seeing the people that didn't*
 27 *make it, we knew that we could be in that situation and God knows how my wife*
 28 *would have coped and and I just hate thinking of [her] being in that situation.”*
 29 *(survivor, age 70, 3 months follow-up)*

1 The concept of “survivors’ guilt” was already present in the first round of interviews.
2 That guilt did not disappear one year on; however, stigma was added on to it [22]. As
3 the pandemic progressed, taking many lives over its course, contracting COVID-19
4 became associated with both stigma and guilt caused by the feeling of not having been
5 “careful enough”. This was particularly concerning to survivors, who were acutely
6 aware of how serious being infected could be, having gone through critical illness due
7 to COVID-19. “(...) you felt guilty that you made it and other people didn’t” (survivor,
8 age 70, 12 months follow-up). As measures were put in place to limit the spread of
9 coronavirus-19, contracting the disease later on in the pandemic perhaps became a
10 sign of disobedience and willingly putting others at risk. The fears and concerns to
11 accessing public spaces remained one year on, which may also reflect the trauma
12 caused by their initial illness and experience of critical care.

13 *“I still find the outside quite scary. I don’t go to the local shops unless I have to. (...) I’m not interested in going in places where people don’t wear mask and have no respect for anyone else’s health” (survivor, age 59, 12 months follow-up).*

16 *“With all these other idiots bumping into you and stuff terrifying me. I hate that. So yeah, going places where I can’t control my own space I would say is the it’s the main issue” (survivor, age 59, 12 months follow-up).*

19 The participants list overcrowded spaces, lack of social distancing and refusal to wear masks as problems which perpetuated the pandemic. Their strong feelings towards lack of public adherence to the protective measures against COVID-19 remain present a year after the initial interviews.

23 *“I’ve done loads of concerts, but it’s just the thought of being in masses of spaces and loads of people I suppose that’s the one lasting effect for me is that I don’t. I don’t yearn to be in a sweaty room full of people watching a concert, or don’t particularly wanna be in an airplane or train, so it’s made, it’s made me very hypervigilant to other people, I suppose, but you know, we have to keep an eye on (...) the virus” (survivor, age 54, 12 months follow-up)*

29 With the rising toll of the pandemic, more pressure may have been put on those who catch and spread the disease, making them feel personally responsible for others’ ill health. The media coverage of the pandemic and public’s behaviour has made the

1 stigma surrounding contracting COVID-19 more prominent, feeding into the narrative
2 of guilt. This in turn may have made talking about their experiences more difficult for
3 the survivors, rendering them unable to process their traumatic illness.

4 **Theme two: Facing the uncertainties of recovery**

5 This theme provides insights into the challenges that survivors and relatives faced
6 over the year past hospitalisation and the support networks they built around and
7 within themselves.

8 For all the interviewed survivors, hospitalisation with COVID-19 was their first
9 experience of severe illness. They were previously mostly healthy, fully functioning
10 and independent individuals. Finding themselves in a new situation, one that was
11 extremely distressing and demanding for their physical and mental health, the
12 survivors struggled with navigating the recovery process after returning home.
13 Furthermore, healthcare professionals **could not** give them a clear prognosis or a
14 timeline for their recovery because they were dealing with an unknown virus.

15 *"it's taking such a long time to get those things back to where I would like to see them*
16 *being, or where they were before I had this. And nobody can tell me whether they will*
17 *ever be truly, you know, back to normal again"* (survivor, age 70, 3 months follow-up).

18 The abrupt and ill-prepared discharge was still at the forefront of the relatives' minds
19 after 12 months had passed. The memory remains significant and traumatic, with the
20 relatives pointing out many faults and omissions at this stage (e.g., no warning prior
21 to discharge, lack of therapy assessments, lack of support for carers).

22 *"I have very strong feelings about [patient being] sent home too early. He wasn't*
23 *physically quite ready for it, even though in his mind he was, and I certainly wasn't*
24 *[ready]. And I was not able to cope properly with him for our first couple weeks"*
25 *(relative, age 50, 12 months follow-up).*

26 According to the survivors, lack of organisation and attentiveness from the busy
27 hospital staff seems to have been a major downfall in the discharge process. Both
28 survivors and relatives reported on how ill prepared they felt at time of discharge from
29 hospital, and how this was a key transition point in their recovery. The participants
30 trusted and relied on the healthcare professionals to help them navigate the new

1 situation of severe illness and were significantly let down in some cases – a
2 disappointment that may persist in their minds throughout further hospitalisations. Self-
3 organising support was complicated by social isolation, either due to fear of re-
4 infection or government rules. The relatives could not access the help from their
5 families or friends, having to face the new caregiver role on their own.

6 Over the course of the follow-up, however, survivors and relatives had more positive
7 experiences to report on. In the follow up interviews, they praised the teams involved
8 in their care throughout hospitalisation and extending into the recovery a year later. *“I
9 did very much feel like, you know [my case] wasn't just a number or a patient. I felt
10 (...) there was a vested interest in my recovery”* (survivor, age 54, 12 months follow-
11 up). Moreover, home visits by the hospital staff made the survivors feel taken care of
12 and validated in their experience of the disease.

13 Survivors mention their support groups as an important part of their journey. Family,
14 local communities and interest groups are amongst those most brought up. **These
15 networks of support were described as important coping mechanism to the trauma of
16 illness and uncertainty of recovery.** As mentioned previously, **however**, access to
17 these networks was significantly hindered by fear of catching or spreading COVID-19,
18 as well as public guidelines. Having recovered from a severe illness, participants
19 began to find new gratitude and appreciation for those around them. *“[Support] from
20 friends and family. (...) We live in a lovely little community where (...) there is moral
21 support and care”* (relative, age 50, 12 months follow-up).

22 Unfortunately, the survivors sometimes struggled to access their support groups.
23 Unable to reach out for help as much as they would have liked, they were forced to
24 look for strength within themselves, reinforcing their identities as survivors. *“I pushed
25 myself to the limit and beyond, and I think because of doing that I've got to where I am
26 today, you know”* (survivor, age 70, 12 months follow-up). Perseverance and resilience
27 became very significant for most participants who continued to create a narrative of
28 overcoming the hurdles of persistent illness. However, as explored in the third theme,
29 the remnants of the disease persist to trouble the survivors 12 months after their
30 discharge.

31 **Theme three: Coping with lingering symptoms – the new norm**

1 Left alone to deal with the unknowns of recovery, the survivors faced frustrations
2 brought on by newly developed symptoms. Unable to return to their lives prior to the
3 illness, they began to search for ways of coping with their difficulties.

4 Most survivors tried to normalise their symptoms by finding rational explanations for
5 their breathlessness, fatigue, and pain. They attempted to laugh their struggles off
6 through light-hearted comments about their age. Meanwhile, some survivors revealed
7 that even after 12 months they had not returned to their hobbies or had to limit their
8 work. Contrasted with the hope of recovery at three months follow-up, at one year the
9 survivors had a bleaker outlook, putting up with the fact they might never return to
10 normality. *“Although I have been disappointed that I can't do some of the things that I
11 could do before (...) but combined with having the virus, [I am] also getting older”*
12 *(survivor, age 70, 12 months follow-up).*

13 Attempting to combat feelings of hopelessness, some survivors began to set smaller,
14 more attainable goals for themselves. **This was a successful way used by some to
15 reach full recovery and get back to normal.** By breaking down the monumental task of
16 a full recovery, they created a sense of achievement, allowing them to progress
17 without feeling disheartened by lingering symptoms. *“Start off with 10 minutes and
18 then keep building up. (...) I think having the goal of doing the bike ride, which I did,
19 was a real boost for me”* (survivor, age 54, 12 months follow-up).

20 To make these achievements more tangible, some survivors reached out for
21 technology, including smartwatches and opportunities for remote consultations offered
22 by clinicians and researchers. Some used oxygen saturations to gauge their limitations
23 and allow themselves to progress at their own pace and continued to do so one year
24 on. *“It's [oxygen saturation] is supposed to be 96% (...) and I know if (...) it goes down
25 to 87% to stop what I'm doing straight away, recover and then carry on”* (survivor, age
26 70, 3 months follow-up). Use of self-monitoring was valued at both three months and
27 one-year follow-ups, being an important part of their daily routines.

28 Thus, while some survivors seemed to have given up on recovery and decided to
29 adjust to their new reality, others continued to strive to make progress towards their
30 health from before the illness. Different levels of resilience among the survivors may
31 have had an impact on the outcomes of their recovery and the steps taken towards it.

1 Throughout their recovery, many survivors began to look for positive aspects of having
2 survived a disease which took millions of lives. Gratitude and acceptance appear as
3 major aspects of patients' new outlook on their new lives, still mixed with guilt for
4 having survived when many did not. *"I came out of that alive and I know that (...) hundreds other people didn't"* (survivor, age 54, 12 months follow-up). This closes the
5 loop to "theme one: The cycle of guilt, fear and stigma", recognising these new feelings
6 as part of the survivors "new norm".
7

8 **DISCUSSION**

9 **Key findings**

10 Studies focusing on the recovery of COVID-19 patients indicate that certain problems
11 persist for a long time after hospitalisation [25]. This report follows the experiences of
12 critical care survivors from the first wave of the COVID-19 pandemic over time to
13 identify their struggles during recovery. Our findings show the feelings of guilt, fear
14 and stigma experienced by the survivors, resulting in a reluctance to share their stories
15 with strangers and accessing public spaces. Moreover, we identified the difficulties the
16 relatives faced due to ill-prepared discharge amidst the disruption caused by the
17 COVID-19 pandemic. We additionally identified factors which the relatives found
18 helpful during that time. Finally, we presented the impact of persisting COVID-19
19 symptoms on the survivors, and the coping methods they implemented amidst the
20 ongoing pandemic.

21 **Relationship to previous studies**

22 Guilt, fear and stigma, explored in the first theme, have been previously reported in
23 the context of the effects of pandemics on mental health. Studies and reviews have
24 begun to explore the parallels between previous pandemics, for example AIDS, and
25 COVID-19,[26–28] finding the feeling of fear of infecting loved ones common among
26 the stakeholders. Consistent with our findings are the results from another qualitative
27 study[29] which presented the narrative of four first-wave COVID-19 patients in India.
28 They found that patients experienced internalised stigma, blame and fear, showing the
29 psychological impact of the pandemic **internationally**. It transpires that the toll of
30 COVID-19 pandemic on survivors' mental health may be common and severe, calling
31 for recognition of and addressing the stigma experienced by the patients through

1 providing public education. In the UK, a report published by the Department of Health
2 and Social Care refers to the changes in the population's behaviour when it comes to
3 seeking health support, for fear of contracting the virus and overwhelming the National
4 Health Service. Our findings support the premise of changed behaviours for those who
5 survived severe COVID-19, supporting wide indirect implications of the pandemic,
6 from which future lessons can be learnt.

7 The tumultuous discharge process remained a significant event after a year had
8 passed, as reported in theme two. These occurrences have been reported previously,
9 nationally and internationally, with many survivors and their carers deeming the
10 hospital discharge process ill-prepared during the COVID-19 pandemic [30]. Some of
11 the hindrances reported by the participants during the COVID-19 pandemic, for
12 example low awareness of survivors' social needs, poor communication and lack of
13 carer support programme, have been previously identified as general barriers to
14 effective hospital discharge planning [31]. Additionally, hesitancy from the survivors'
15 families has been identified as one of the emergent factors during the COVID-19
16 pandemic [32]. Moreover, the relatives' experience was complicated by their social
17 isolation during the pandemic – a phenomenon which had been previously reported
18 among dementia caregivers in the COVID-19 pandemic[33]. While the barriers to an
19 uncomplicated discharge process have changed with the onset of the pandemic,
20 efforts should still be made to provide support for the carers prior to, during and after
21 the hospital discharge.

22 Studies have previously identified the positive impact of high resilience and self-
23 efficacy in the recovery of ICU survivors [15,34,35] improving the psychological
24 sequelae and ability to manage the activities of daily living. The exact role of resilience
25 in post-ICU recovery, as well as the impact of the COVID-19 pandemic on patients'
26 resilience has not yet been explored. There is, however, research into similar issues
27 in conditions such as diabetes[36] and asthma [37]. It is important to consider the
28 implications of survivors' "inner strength" in their recovery during a time where much
29 of the follow-up may have been inadequate and the information given insufficient [30].
30 Techniques to develop survivor resilience could be used to relieve some of the strain
31 put on health and social services, creating a patient-led recovery programme.

1 As many as 1.1 million people living in the UK have reported persistent symptoms
2 after a COVID-19 infection [38] – a syndrome which has become known as ‘long
3 COVID-19’. Researchers report that ICU COVID-19 survivors experience many
4 physical, cognitive and psychological problems a year after their hospitalisation [40].
5 Those affected by the aftermath of their illness have had to develop coping
6 mechanisms, as identified in theme three. Chahraoui *et al.*[39] have explored similar
7 phenomena among ICU survivors where humour and an optimistic approach were
8 used by some of the participants to combat the feelings of hopelessness and anxiety.
9 Other studies identified distraction, self-effectiveness, social support and maintaining
10 a positive outlook about the illness as helpful coping mechanisms[40]. Despite these
11 coping mechanisms, some of our participants mention their inability to completely
12 recover due to old age. Previous research has shown that older adults indeed struggle
13 to return to their pre-morbid function, after acute illness [41]. Further research into the
14 effectiveness of other coping mechanisms mentioned in our study, like setting short-
15 term goals to reach recovery objectives is needed to evaluate whether these methods
16 could be promoted as effective for the patients.

17 **Strengths and limitations**

18 This study provides in-depth insights into the experiences of COVID-19 critical care
19 survivors over time. Longitudinal follow-up of the recovery journey permitted an
20 understanding of the progression of these stakeholders. The focus on the survivors
21 from the first wave of COVID-19 provided insight into the initial population of COVID-
22 19 critical care survivors who were recovering while the disease was initially being
23 researched. Participants were given the choice to be interviewed by video call or
24 telephone. This enabled participants to take part in a way they felt most comfortable.
25 Although video calls can allow for an easier engagement between participant and
26 researcher, data on non-verbal clues was not analysed, giving the data a similar depth,
27 regardless of the data collection method (phone Vs video call).

28 Several limitations should be acknowledged. The small sample size may have reduced
29 the transferability of the results to a wider population. The transferability was also
30 affected by the sample selection – patients and relatives affected during the first wave
31 may have had different experience of the critical illness compared to those from
32 subsequent waves. Moreover, only one of the relatives responded to the invitation to

1 complete the follow-up interview at one year, making them an under-represented
2 group. This reflects the challenges of recruiting to follow up qualitative studies. We
3 have also reflected on this as a team and will look at our recruitment strategies to
4 improve this in future studies. Only female relatives were recruited by the participants.
5 This was a limitation of the snowballing strategy used, in which survivors invited a
6 carer to be interviewed. All survivors chose to invite female carers. Male relatives may
7 have presented different experiences of providing care. In the future, a more diverse
8 relative sample could be used to present varied perspectives of the caregivers.

9 **Recommendations**

10 Following the results of this study, along with other studies into the experiences of
11 COVID-19 critical care survivors, these patients would benefit from a follow-up and
12 support regarding their mental health after hospital discharge[30,31]. Moreover,
13 discharge process should be carefully planned and actively involve informal carers in
14 order to minimise carers' stress[32]. Access to therapy assessments, equipment and
15 technologies were mentioned by the participants as contributing factors to a smoother
16 transition from hospital to home. We also recommend further investigation into the
17 coping mechanisms and their effectiveness among COVID-19 critical care survivors.
18 Identification of helpful strategies to cope with the burden of long COVID-19 could aid
19 effective and patient-centred discharge planning and onward support in the community.
20 Future studies could be expanded to include the first and subsequent waves of the
21 COVID-19 pandemic.

22 **CONCLUSION**

23 This study focused on the experiences of a small sample of patients and their relatives
24 over a year after hospital discharge from critical care following an admission with
25 COVID-19, during the first wave of the pandemic. The patients were found to feel guilt,
26 fear and stigma which made them reluctant to talk about their experiences. Faced with
27 long-haul symptoms of COVID-19, patients used coping mechanisms like humour and
28 setting goals. The relatives described the challenges faced with ill-prepared
29 discharges during the first wave of the pandemic and the value of support systems for
30 both stakeholders when confronted with life-limiting illness. These conclusions should
31 be taken into consideration when formulating optimal recovery for patients with

- 1 COVID-19, as well as when exploring the psychological toll of being affected during
- 2 the first wave of the COVID-19 pandemic.

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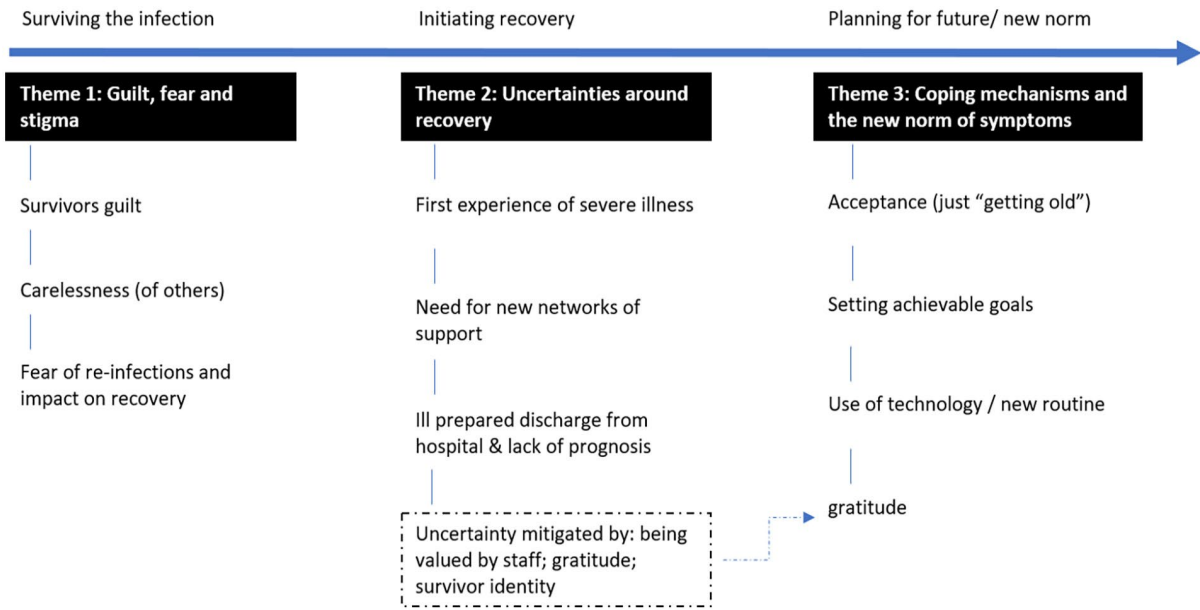
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1 **Figures**



2

3 **Figure 1.** Recovery journey of COVID-19 ICU patients during the first wave of the
 4 pandemic – a year on after hospitalisation.

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