

## RESEARCH ARTICLE

# Surviving severe COVID-19: Interviews with patients, informal carers and health professionals

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## Abstract

**Background:** The COVID-19 pandemic has been associated with an unprecedented number of critical care survivors. Their experiences through illness and recovery are likely to be complex, but little is known about how best to support them. This study aimed to explore experiences of illness and recovery from the perspective of survivors, their relatives and professionals involved in their care.

**Study design:** In-depth qualitative interviews were conducted with three stakeholder groups during the first wave of the pandemic. A total of 23 participants (12 professionals, 6 survivors and 5 relatives) were recruited from 5 acute hospitals in England and interviewed by telephone or video call. Data analysis followed the principles of Reflexive Thematic Analysis.

**Findings:** Three themes were generated from their interview data: (1) Deteriorating fast—a downhill journey from symptom onset to critical care; (2) Facing a new virus in a hospital—a remote place; and (3) Returning home as a survivor, maintaining normality and recovering slowly.

**Conclusions:** Our findings highlight challenges in accessing care and communication between patients, hospital staff and relatives. Following hospital discharge, patients adopted a reframed 'survivor identity' to cope with their experience of illness and slow recovery process. The concept of survivorship in this patient group may be beneficial to promote and explore further.

**Relevance to clinical practice:** All efforts should be made to continue to improve communication between patients, relatives and health professionals during critical care admissions, particularly while hospital visits are restricted. Adapting to life after critical illness may be more challenging while health services are restricted by the impacts of the pandemic. It may be beneficial to promote the concept of survivorship, following admission to critical care due to severe COVID-19.

## KEYWORDS

critical care, long term recovery, multi-disciplinary team, rehabilitation, SARS-CoV-2

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## 1 | INTRODUCTION

To date, more than 36 000 people have been admitted to intensive care units, in England, Wales and Northern Ireland, while testing positive for COVID-19.<sup>1</sup> Each wave of infection is inevitably followed by a wave of survivors of critical illness with potentially high rehabilitation needs. Understanding the process of illness, survival and recovery post-critical illness due to COVID-19 is therefore urgently needed.<sup>2,3</sup>

The sequelae of critical illnesses are well known,<sup>4,5</sup> but the optimal recovery pathway is yet to be defined.<sup>6,7</sup> Similarly, the sequelae of COVID-19 infections are now beginning to be identified, including a range of cardiac, respiratory, vascular, endocrine and neurological symptoms.<sup>8-10</sup> Yet recovery prognostics and optimum standards of rehabilitation are less clear.<sup>11,12</sup> Further, their pathway to survival and recovery as well as their access to health care has, and will be, altered by social distancing measures and additional pressures on health and social care during and after the pandemic.<sup>13</sup> Experiences of illness, survival and recovery for those admitted to intensive care units with COVID-19 will include unique challenges compared to those who have survived critical illness prior to the pandemic. Those in intensive care units with COVID-19 faced a novel virus, alongside healthcare professionals adapting to a world pandemic and with very limited support from their loved ones, due to restricted hospital visits. Once discharged home, they might have faced challenges in accessing care in the community as services recover from the effects of the pandemic.<sup>13</sup>

In this context, the experiences of those who survived severe COVID-19 and are now on their journeys towards recovery, as well as those of their informal carers and health professionals, can provide invaluable insight into trajectories of recovery post severe COVID-19. Their views can inform on how best to support the rehabilitation process of those surviving a severe COVID-19 in the future, as well as those recovering from critical illness while health services are affected by the pandemic. Some qualitative studies have begun to explore the experiences of health care professionals, patients and family members during the COVID-19 pandemic.<sup>14-21</sup> However, these qualitative accounts focus on other aspects of health care, such as experiences of care received only in hospital,<sup>14,15,19-21</sup> working on the frontline of the pandemic,<sup>16-18</sup> being discharged from critical care prior to the pandemic,<sup>22</sup> or recovery from less severe forms of COVID-19.<sup>11</sup> Therefore, despite the growing body of qualitative literature on this topic, the experiences of survival, recovery and rehabilitation from severe COVID-19 infection, from the perspectives of the three key stakeholder groups involved in the rehabilitation process (patients, informal carers and health professionals) are yet to be fully explored.

The present study aims to gain an in-depth understanding of the experiences of illness, survival and early stages of recovery from the perspective of survivors of severe COVID-19, their informal carers and health professionals, in order to inform the care needs of this patient group.

### What is known about this topic

- Those surviving critical illnesses are often left with important sequelae and rehabilitation needs.
- The COVID-19 pandemic led to both an increase in the number of survivors of critical illness and a decrease in the rehabilitation services offered in the community.
- Understanding the experiences of those involved in the recovery process post-critical illness is essential to improve future patient care.

### What this paper adds

- All efforts should be made to continue to improve communication between patients, relatives and health professionals, particularly while hospital visits are restricted.
- Adapting to life after critical illness might have been more challenging during the pandemic. Patients and relatives may require additional support, particularly while social distancing measures are in place and health services are recovering from the impacts of the pandemic.
- It may be beneficial to promote the concept of survivorship, following admission to critical care due to severe COVID-19.

## 2 | DESIGN AND METHODS

### 2.1 | Design

During the first wave of the COVID-19 pandemic (March–May 2020), five acute general hospitals in the South-East of England initiated a research study to observe the process of recovery of people who survived critical illness due to COVID-19, up to 1 year following hospital discharge. As part of this larger study,<sup>23</sup> we conducted in-depth qualitative interviews with three groups of stakeholders: survivors, informal carers and health care professionals, across the five hospital sites included in the study. Their narratives explored experiences of critical illness in the early days of the pandemic and the first three months of their rehabilitation. The present study followed the Consolidated Criteria for Reporting Qualitative Research.<sup>24</sup>

### 2.2 | Sampling and recruitment

Participants from the three stakeholder groups were recruited between May and July of 2020. Detailed inclusion and exclusion criteria can be found in the study protocol.<sup>23</sup>

Health professionals were recruited in all hospital sites through the participant information sheet being shared with team leads of

physicians, nurses and therapists working with survivors of critical illness due to COVID-19. A maximum variation sample strategy<sup>25</sup> was used. Based on the clinical expertise of the authors, it was re-established that the key professionals in this stakeholder group should include physicians, nursing staff and therapists, both male and female, with a range of years of experience and from the different hospital sites included in the study. Professionals were recruited from the same hospital sites as the survivors. Therefore, they were part of the clinical teams treating all the interviewed survivors, but may or may not have been directly involved in the care of the survivors who were also part of this study. The decision to include professionals beyond those who treated the survivors included in this study was made in order to maximize the recruitment of professionals during the pandemic. It was anticipated recruitment of this stakeholder group to be potentially challenging due to the burden of health care professionals at the frontline of the pandemic. Keeping recruitment open to all professionals working with critical care patients who tested positive for COVID-19 (and not just those caring for the survivors who took part in this study) facilitated recruitment and allowed for professionals with a variety of clinical backgrounds and experiences to be included.

Survivors were eligible to be interviewed if they met the following inclusion criteria: age 18 or over, having required either invasive or non-invasive ventilation as a result of confirmed COVID-19, and with at least moderate severity of acute respiratory distress syndrome (PaO<sub>2</sub>/FiO<sub>2</sub> ratio of ≤26.6 kPa or ≤200 mmHg). Clinicians working with the research team in each of the included hospital sites invited their patients who met these criteria to be interviewed following a maximum variation strategy accounting for age, gender, mode of mechanical ventilation and hospital length of stay. Participants consented to be contacted about a future interview, while they were in the hospital. The interviews were conducted when the participants/survivors were at home; approximately 3 months post their discharge from intensive care units. Formal consent was gained and audio recorded immediately prior to the interview. Conducting the interviews at this point in time allowed survivors to report on their journeys up to the early stages of rehabilitation at home.

A snowball recruitment strategy<sup>26</sup> was then used as survivors were asked to, if they wished to do so, invite a relative or friend, who had been part of their rehabilitation journey to be interviewed as well, either in joint or separate interview, according to their preference.

The sample size was determined, not on data saturation, but on reaching a rich data set, from participants with a variety of demographic characteristics (as detailed above).

## 2.3 | Interview procedures

Semi-structured interviews were conducted following a topic guide (available on request), developed by the authors ACG and CK.

Two dyads (survivor-relative) were interviewed together. All other participants were interviewed on a one-to-one basis by ACG, PhD, by telephone or video call and were audio-recorded. ACG is a female researcher with experience in conducting qualitative

interviews and a physiotherapist who works in one of the acute hospitals included in this study. The interviewer had a pure research role at the time of data collection and had no previous contact with any of the potential participants. The interviewer introduced herself to all research participants before the interview and all participants were aware of her clinical background and role at the time of the interview.

## 2.4 | Analysis

Data collection and analysis were conducted under the conceptual underpinning of critical realism and contextualism. All qualitative interviews were audio-recorded, transcribed verbatim and analysed following principles of Reflexive Thematic Analysis.<sup>27</sup> NVivo (Release 1.4.1, QSR International, Pty Ltd) was used to aid data organization. The six steps of Reflexive Thematic data analysis were followed<sup>27</sup>—see Box 1. The first step of the analytic process was data familiarization. All interviews were conducted and manually transcribed by ACG. This provided an opportunity for data familiarization. Reflective logs were kept to report on possible assumptions as well as initial aspects of interest triggered by this initial exposure to the data. A subset of six transcripts was also read by CK and AW, who familiarized themselves with part of the data set ahead of analytical discussions within the team. All transcripts were initially coded by ACG. These were inductive or data-driven codes, initially very close to the participants' own words. A subset of six interviews was also coded by CK and AW. These six interviews were then discussed by the three co-authors. These discussions took place simply to promote 'thinking aloud' and stimulate more in-depth interpretations of the data. After these discussions, more latent codes were generated. The whole data set was then re-read and recoded with more latent codes by ACG. Regular discussions were kept with CK and AW, and supported by the use of a reflective diary in order to work towards the generation of themes. Once preliminary themes were created, member checking<sup>28</sup> was conducted with one participant from each stakeholder group, which further developed the final thematic map (Figure 1). Writing the findings section is, in fact, an active stage of analysis, and the last phase of the six phases described by Braun and Clarke (2020). After several iterations of writing, discussions between all co-authors and

### BOX 1 Six steps of reflexive thematic analysis by Braun and Clark<sup>27</sup>

1. Data familiarization and writing familiarization notes;
2. systematic data coding;
3. generating initial themes from coded and collated data;
4. developing and reviewing themes;
5. refining, defining and naming themes; and
6. writing up the findings.

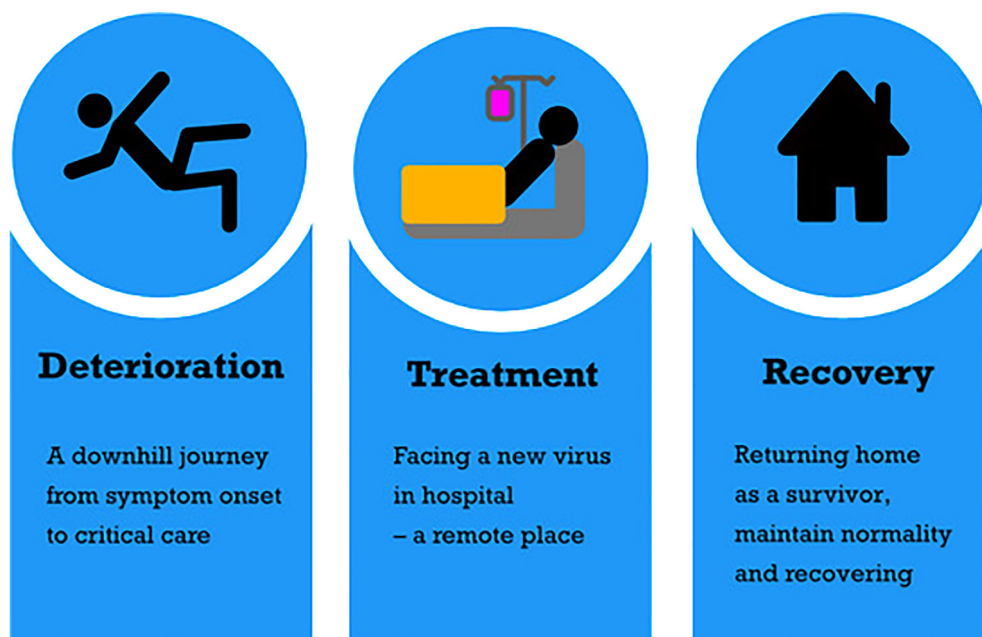


FIGURE 1 Thematic map

final ‘checks back’ to the original data set, the analysis was refined. At this stage, Figure 2 was created to highlight the roles of the three stakeholder groups across the themes and through their journeys of illness, survival and recovery.

## 2.5 | Ethics statement

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

## 3 | FINDINGS

### 3.1 | Sample characterization

A total of 23 participants (12 professionals, 6 survivors and 5 relatives), across 5 different acute hospitals, were interviewed. Further detail on the characteristics of the participants can be found in Table 1. The interviews had a mean duration of 57 min (ranging from 38.43 to 72.22 min).

### 3.2 | Experiences of illness, survival and recovery from the perspectives of survivors, relatives and professionals

Three themes were generated to explain the experiences of illness and recovery from the perspectives of all three stakeholder groups (Figure 1). The first theme, ‘Deteriorating fast—a downhill journey from symptom onset to critical care’, sets the scene by bringing into

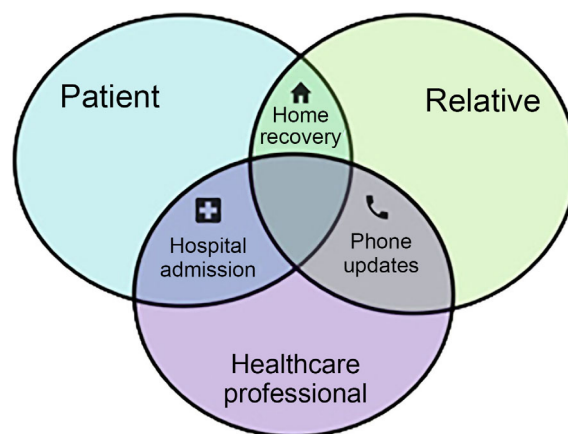


FIGURE 2 Roles of three stakeholder groups in the journey of survival

light how survivors quickly deteriorated and became critically ill. The second theme ‘Facing a new virus in hospital—a remote place’ illustrates recovery in the hospital, while professionals adapted fast to the pandemic and relatives, without visiting rights, desperately tried to communicate. The last theme ‘Returning home as a survivor, maintain normality and recovering slowly’ enlightens the first months of recovery at home, during ongoing social isolation. The roles of the different stakeholders in the process of survival and recovery following severe COVID-19 are illustrated in Figure 2.

#### 3.2.1 | Theme one: Deteriorating fast—a downhill journey from symptom onset to critical care

The survivors included in this study had important memory gaps regarding the period of time between symptom onset and their

**TABLE 1** Sample characterization

Role: Professionals (n = 12)	N (%) or mean (±SD)
Gender (male)	4 (33%)
Age	37 (±10.5)
Professional background	
Physiotherapist	3 (25%)
Occupational therapist	1 (8%)
Physician	3 (25%)
Nurse	2 (16%)
Speech and language therapist	1 (8%)
Dietitian	2 (16%)
Years of experience	14 (±10.2)
Role: survivor (n = 6)	N (%) or mean (±SD)
Gender (male)	4 (67%)
Age (years)	65 (±7.5)
Hospital length of stay (days)	23 (±10.9)
Number of days in intensive care	14 (±10.8)
Ethnicity	
White British	5 (83%)
Other ethnicities	1 (17%)
Previously in paid employment	3 (50%)
Discharged home from hospital	6 (100%)
Role: relative or friend (n = 5)	N (%) or mean (±SD)
Gender (male)	0 (0%)
Age	59 (±9)
Relationship to the survivor	
Spouse or partner	3 (60%)
Child	1 (20%)
Friend	1 (20%)

admission to critical care. This first theme described their experience of becoming seriously ill, told by survivors and their relatives, who helped fill in the gaps.

Participants' reports, at the beginning of the pandemic in the UK, demonstrate a high level of awareness of the likely diagnosis of infection with COVID-19, even before tests were easily available in the community. Contrasting with this very acute awareness of what their symptoms might mean, was uncertainty about how to manage or treat the disease, beyond any measures to contain it. Exacerbating their fear and uncertainty—already fuelled by the constant media headlines—survivors and relatives faced resistance to accessing care as symptoms deteriorated. Relatives of those infected in the community described, without exception, difficulties in getting help to their loved ones. Multiple attempts and long waiting times to be able to speak with a health professional, having to insist on having their relative while being taken into hospital, or being questioned about how appropriate their 999-call was, were common events in their narratives of the first few days of living with the virus. Survivors and relatives explained how they finally received help once when they were

at a breaking point and were admitted to critical care briefly after saying their short goodbyes at the back of an ambulance.

I know the 111 [urgent care advice number in the UK] were under such pressure with the volume of calls, but when you are on the phone for over an hour or two hours trying to get through... in desperation, really and all they say is: isolate. People aren't really seeing how bad you are [...] if it wasn't for my wife making that phone call [to 999] I would not be here today, [...] and that is getting too near the knuckle, really too close for comfort. [Survivor, male, 70 years old]

In the back of ambulances, relatives described being left worrying about their loved ones, but also about the possibility of being infected themselves. Many had to self-isolate, and all lost their own networks of support as national lockdown measures came into action.

Well, I think [it was] difficult, because being in isolation that I had nobody around to kind of discuss it with them, or talk to. [Relative, female, 52 years old]

### 3.2.2 | Theme two: Facing a new virus in a hospital—a remote place

This theme reflects the experiences of survivors, relatives and professionals within the hospital setting. Once again, survivors have memory gaps about this period of their journey but reflect on the symptoms they endured and milestones of recovery. Various coping strategies, to deal with illness and separation from their loved ones were present in their narratives: peer support from fellow patients on the wards, faith, spiritual and emotional support from staff and remote communication with relatives, using technology when this was available.

The earliest positive memories were (...) ICU had a tablet and then [my wife and I] would face time on the tablet. So that was a fantastic touch, to be able to finally communicate with her. [Survivor, male, 54 years old]

Communication with the hospital was a lifeline for the relatives interviewed. They reported overwhelming frustrations as they struggled to communicate. Relatives often felt passive recipients of generalized information, causing challenges in both understanding and interpretation of the patient's progress.

...and they just say, you know 'he is stable' or 'he is sleepy' or something. I suppose if there is nothing else to say, there is nothing else to say. But it is not much when you are at the other end of the phone and just want to know what is going on medically. [Relative, female, 66 years old]

The difficulty communicating with the hospital and then passing that information on to extended family and friends was also a trigger for anxiety and a big part of their workload in their new caring role.

The difficulties experienced by relatives in communicating with the hospital were well understood by professionals, and something they worked hard to improve. Efforts were rapidly made to implement technology to allow better communication with 'relatives in the outside world'. In fact, as visits were not allowed, communicating with families was no longer a natural, fluid part of their day-to-day job and became an additional emotionally-heavy task, added on to their already heavy workload.

I think [communicating with families] is vitally important, I think it is emotionally exhausting if you were to do it continuously. I think they [junior doctors] might have found it hard, after a while. [Physician, male, 40 years old]

The professional group is heard in this theme not only as highly skilled and providing exceptional care, but also vulnerable and stressed, as they struggled to manage a surge in critically ill patients, against an aggressor as yet to be fully understood, requiring constant learning and adaptation. The large number of patients requiring significant support challenged professionals to the point of mental and physical exhaustion.

...For the ICU staff because obviously, (...) I was not there, I was only getting a phone call, and I would ask them how they were (...) obviously they would tell me they were ok (...) But I had seen in the media the stress it was putting the hospitals under and the staff because of the conditions you were working under and the fact that it's so new, and the fact that there weren't any family members there to support with the patients. So the nursing staff were having to do emotional support as well. [relative, female, 52 years old]

Despite the knowledge of staffing shortages and no holiday coming, just the requirement to keep going in an uncertain and fluctuating landscape, professionals continued to develop mechanisms of support for each other and gained a greater understanding and wider appreciation of others' roles. In addition, professionals also described positive changes to the way they worked. They became more agile at implementing changes and collaborating with others.

I think, I think a lot of red tape has been sort of, you know, cut and brushed aside (...) I think it has allowed people to just actually say 'well, let's do it'. You know, in good communication, let's try it. (...) that's not always that easy to make change sometimes in the NHS (National Health Service in the UK). [Physician, male, 55 years old]

### 3.2.3 | Theme three: Returning home as a survivor, maintaining normality and recovering slowly

As described in theme two, hospitals became remote, isolated places during the pandemic. Leaving the hospital to return home was an important milestone for all involved.

For professionals, discharge planning was more complex than usual as health and social care services were rapidly changing the way care was delivered, to adapt to the pandemic. Discharge decisions also had to be made at a record time in response to the pressure to empty hospital beds.

As soon as anyone wrote: 'medically fit for discharge', they were gone. And (...) that was very different and quite difficult to manage sometimes because (...) you can put someone in a short-term placement, who could be home within three days. (Occupational therapist, Female, 36 years old)

All patients longed to leave the hospital and go home to their loved ones. Some wanted to be discharged at any cost. Others made selfless decisions of going home and self-isolate for fear of infecting their loved ones and withdrawing support from their family.

all I wanted to do was to come home. I didn't understand or appreciate how weak she was... [to care for me]. (Survivor, male, 67 years old)

The interviewed relatives described receiving the news of their discharged loved ones with huge relief. But some felt ill-prepared to care for their loved ones back home, or feared they were being discharged too soon. Seeing their loved ones for the first time after weeks of hospital admission and no face-to-face contact was reported as a great shock. Professionals agreed relatives needed a debrief before seeing their loved ones again, something they attempted to do remotely but was not always possible.

The person that you love, that was previously independent now needs help from you, they are short of breath, they have to eat an especially soft diet, they have thickener in their drinks, they are struggling to walk and you haven't seen them in all this time, you haven't seen this happen and you thought they were going to die twice! (Speech and language therapist, Female, 23 years old)

Once at home, recovery was described as very slow and full of unknowns. Neither survivors nor relatives or professionals knew what to expect or how best to support rehabilitation 'back to normal' and that uncertainty was a heavyweight to carry.

'It would have been nice to have a face-to-face chat with the doctor (...) and for them to say you know, expect your mother to be very tired, or don't expect

too much from her too soon. (Relative, female, 50 years old)

The burden of the recovery process was increased by the severity of the sequelae (for instance severe shortness of breath, fatigue and psychological trauma) and the limited support from community services, extended family or peers, restricted by social isolation measures. Those who had access to hospital follow-up services were grateful and reassured by the regular contact with professionals. Staff involved in such follow-ups greatly valued the opportunity of seeing patients recovering and wished for more joint work with community teams.

'I mean, in an ideal world it would be lovely to continue that little bit...you know, from the hospital, outreaching for them at home for a little bit before they were passed on to a team and obviously being able to do that in a real joint up way'. (Occupational therapist, Female, 36 years old)

Narratives of patients about their recovery journeys, from their admission to critical care to their first few weeks at home, were rich in words that allude to a 'war against the virus' (e.g., fighting the disease, is determined to improve, not wanting to be seen as 'sick', pushing oneself and not wanting to be stopped by the virus), suggesting a process of reframing their identity as survivors, whilst aiming to return to previous life roles and maintain normality.

That's where they put the hood on me and they connected me up to everything they needed to and we just soldiered on. (...) But I don't think I would be where I am today, if it hadn't been for my very, very hard work indeed. (Survivor, Male, 70 years old)

In line with this reframed 'survivor' identity, participants recall positive episodes of camaraderie as some kept in touch with fellow patients after their discharge. Patients also describe new outlooks on life and a deep sense of gratitude for being alive. Those still facing mental illness as sequelae of severe COVID-19 expressed feelings of guilt for having survived, when so many others did not.

'They have had 18 very poorly, in my situation: had COVID, on a ventilator and in a coma. Five of them are dead [crying] why not me? They would have been better people than me! And you get this... you know, PTSD (Post Traumatic Stress Disorder). And I don't deal with that very well actually'. (Survivor, Male, 59 years old)

## 4 | DISCUSSION

This is a unique study providing an in-depth understanding of the process of illness, survival and early recovery post severe COVID-19, integrating the views of all key stakeholders involved in the process of survival and recovery: survivors, informal carers and health

professionals. Our findings show how patients and families at the beginning of the pandemic struggled to access help to manage their symptoms; how they quickly became critically ill; and how relatives in the 'outside world' struggled to communicate with their loved ones and professionals in the hospital. It also highlights the burden of the pandemic on healthcare professionals and how survivors of critical illness are slowly recovering, towards a reframed 'survivor identity'.

Challenges in accessing care at the beginning of the pandemic, reported by survivors and informal carers in the first theme, highlight problems in accessing health remotely, which continue to be reported worldwide. A recent literature review highlighted how the use of telecare expanded rapidly during the pandemic, providing an opportunity to evaluate these forms of health care.<sup>29</sup> Our findings, from the first wave of the pandemic, suggest shortcomings in remote triage of patients, though further research is necessary to elucidate whether these have subsequently been addressed.

Communication, explored in theme two, was a key aspect all stakeholders wished to see improved and maximized in the hospital. Having a loved one at the bedside is a common first memory of critical care survivors.<sup>30</sup> The inability to have close contact with relatives during hospital admissions was a great challenge reported in this study, but also in other parts of the world.<sup>14,15</sup> The development of novel services and strategies to address the gap in communication created by restricted hospital visiting measures has been reported internationally.<sup>21,31</sup> Maximizing communication and contact with loved ones should remain a high priority. In the absence of family, professionals described the added responsibility of providing emotional support to survivors. This and other burdens on professionals, described in theme two, are in line with those reported in other qualitative studies,<sup>16,17,32</sup> adding to the body of evidence documenting the efforts of those on the frontline of the pandemic.

Lastly, the third theme addressed the transition of care from hospital to home. Professionals would have valued the opportunity to follow the patient journey and get to know how much they had improved and achieved. This is in line with previous literature reporting on the challenges faced by critical care staff who witness the early stages of patient survivorship but are limited in the support they can offer with the patient's ongoing needs.<sup>33</sup> Based on these findings, it may be hypothesised that having the opportunity to follow patients for a long term in their survivorship journey may be beneficial to staff wellbeing. For patients and families, returning home gradually leads to a reframed 'survivor identity'. The concept of 'survivor identity' is well established in the cancer literature<sup>34,35</sup> and it has recently been explored in critical care survivors in general.<sup>30,36-38</sup> 'Survivorship' has been described as a different concept from 'recovery'. Recovery implies being 'cured' and back to life as it was, prior to illness. 'Survivorship' means re-engaging with a life that is different.<sup>36</sup> Interestingly, the participants in this study told narratives of 'survivorship', as their recovery is yet to be completed. Corner, Murray and Brett<sup>30</sup> theorized the rehabilitation journeys post-critical illness, as a process of 'recalibration' for survivors, in which they adjust their current and future selves to a new reality. The data here presented may suggest how the process of 'recalibration' post-critical illness was made more challenging during the pandemic. Professionals were not

able to guide survivors regarding what to expect and relatives might have struggled to readjust their own expectations, after the shock of seeing their loved one face to face for the first time on the day of discharge. The process of creating a survivor identity has also been linked to better mental health as well as engagement in health promotion activities.<sup>34</sup> This is in line with our findings that suggest the creation of a 'survivor identity' as a possible coping mechanism for understanding their own experience of illness as well as their current state of disability. A survivor's identity may also help to explain the feelings of guilt for having survived, whilst having witnessed others dying from the same disease. Other qualitative studies include quotations from those who are discharged from critical care units alluding to this concept of 'survivorship as a positive coping strategy'. For instance, a quote from a family member included in the study by Major et al. 'The ambulance nurse said to Florence: madam, I am honored that I can drive you. Most patients with your condition leave the hospital on a different transport. [...] And I thought, what a compassionate thing to say. I was touched by it, felt understood for the first time'.<sup>22</sup> Our findings, therefore, add to a preliminary definition of survivorship from critical illness suggested by Kean et al.,<sup>38</sup> by recognizing the process of reframing one's identity as a 'survivor' as a possible positive coping strategy. In line with these findings, we suggest 'survivorship' in severe COVID-19 might be an important concept to promote by health professionals and in public health messages.

#### 4.1 | Strengths and limitations

Interprofessional teamwork and active engagement of relatives and friends have been reported as essential to the rehabilitation of critical care survivors.<sup>39,40</sup> The present study integrates the views of health professionals from different clinical backgrounds as well as those of relatives and survivors, as the key stakeholders in rehabilitation post-critical illness. Following rigorous qualitative methodology (Consolidation criteria for reporting qualitative research checklist as supplementary file), our findings provide valuable insight into the complex process of survival and recovery post severe COVID-19 and assist health professionals and researchers in the design of rehabilitation pathways for this population.

The present work is not without limitations. Survivors were asked to identify a relative or friend who had been key to their recovery journey to take part in this study. Coincidentally, all survivors chose to invite a female relative or friend to be interviewed. Male relatives might have different views on supporting someone's recovery post severe COVID-19. To address this, additional efforts will be made in the follow-up part of this project, after a year post-hospital discharge, to invite male relatives or friends to be interviewed. Whilst including professionals from different clinical backgrounds and from multiple hospital sites is strength of this study, only professionals from acute hospitals were included and professionals working in the community were missed. In order to minimize this limitation, some of the included professionals did outreach work with survivors in the community, continuing to support survivors after their discharge from the hospital. Future work should include professionals from community settings, involved in supporting more closely the rehabilitation of survivors of

severe COVID-19 post-hospital discharge. The present study only included a small sample of participants, from a small number of hospitals in the South of England. Future research on this topic remains necessary in other settings and contexts.

## 5 | CONCLUSION

During the first wave of the COVID-19 pandemic in the UK, survivors and relatives reported challenges in accessing care and in maintaining communication between the hospital and the outside world. Professionals, aware of the vital importance of communication, described important efforts to keep regular contact with families while being overwhelmed by the workload on the frontline against the new virus. Three months following hospital discharge, survivors had adopted a survivor identity to help work towards their recovery. These accounts should be considered in the planning to assist the recovery of critical care survivors during and post-pandemic.

### AUTHOR CONTRIBUTIONS

All authors made important contributions to the present manuscript and have read and approved its final version. Specific contributions can be listed as follows: study design and conceptualisation: Ana-Carolina Gonçalves, Christina Koulouglioti, Annabel Williams, Luke Hodgson; recruitment and data collections: Ana-Carolina Gonçalves, Todd Leckie, Alexander Hunter, Daniel Fitzpatrick, Benjamin Hardy, Christina Koulouglioti; Data analysis: Ana-Carolina Gonçalves, Christina Koulouglioti, Annabel Williams; writing of the first draft: Ana-Carolina Gonçalves, Christina Koulouglioti, AW; editing of the manuscript, including the development of figures and tables and making comments to data analysis and discussion: Ana-Carolina Gonçalves, Annabel Williams, Christina Koulouglioti, Todd Leckie, Alexander Hunter, Daniel Fitzpatrick, Alan Richardson, Benjamin Hardy, Richard Venn, Luke Hodgson.

### DATA AVAILABILITY STATEMENT

Anonymised interview transcripts can be made available on request.

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### REFERENCES

- Intensive Care National Audit and Research Centre. ICNARC report on COVID-19 in critical care: England, Wales and Northern Ireland May 10, 2021. ICNARC COVID-19 Study Case Mix Program Database [Internet] 2020; 2021:1-16. <https://www.icnarc.org/Our-Audit/Audits/Cmp/Reports>.
- Hosey MM, Needham DM. Survivorship after COVID-19 ICU stay. *Nat Rev Dis Primers*. 2020;6(1):1-2. doi:10.1038/s41572-020-0201-1
- Prescott HC, Girard TD. Recovery from severe COVID-19 leveraging the lessons of survival from sepsis. *JAMA*. 2020;324(8):739-740.
- Herridge MS, Tansey CM, Matté A, et al. Functional disability 5 years after acute respiratory distress syndrome. *N Engl J Med*. 2011; 364(14):1293-1304.
- Hamilton M, Tomlinson G, Chu L, et al. Determinants of depressive symptoms at 1 year following ICU discharge in survivors of  $\geq 7$  days



- of mechanical ventilation: results from the RECOVER program, a secondary analysis of a prospective multicenter cohort study. *Chest*. 2019;156(3):466-476.
6. Mehlhorn J, Freytag A, Schmidt K, et al. Rehabilitation interventions for postintensive care syndrome: a systematic review. *Crit Care Med*. 2014;42(5):1263-1271.
  7. Connolly B, Denehy L, Brett S, Elliott D, Hart N. Exercise rehabilitation following hospital discharge in survivors of critical illness: an integrative review. *Crit Care*. 2012;16(3):226.
  8. Daugherty SE, Guo Y, Heath K, et al. Risk of clinical sequelae after the acute phase of SARS-CoV-2 infection: retrospective cohort study. *BMJ*. 2021;373:1-12.
  9. Musheyev B, Borg L, Janowicz R, et al. Functional status of mechanically ventilated COVID-19 survivors at ICU and hospital discharge. *J Intensive Care*. 2021;9(1):1-10.
  10. van Veenendaal N, van der Meulen IC, Onrust M, Paans W, Dieperink W, van der Voort PHJ. Six-month outcomes in covid-19 icu patients and their family members: a prospective cohort study. *Healthcare*. 2021;9(7):1-15.
  11. Shelley J, Hudson J, Mackintosh KA, et al. 'I live a kind of shadow life': individual experiences of COVID-19 recovery and the impact on physical activity levels. *Int J Environ Res Public Health*. 2021;18:11417.
  12. Goodwin VA, Allan L, Bethel A, et al. Rehabilitation to enable recovery from COVID-19: a rapid systematic review. *Physiotherapy*. 2021; 111:4-22. doi:[10.1016/j.physio.2021.01.007](https://doi.org/10.1016/j.physio.2021.01.007)
  13. Castro-Avila AC, Jefferson L, Dale V, Bloor K. Support and follow-up needs of patients discharged from intensive care after severe COVID-19: a mixed-methods study of the views of UK general practitioners and intensive care staff during the pandemic's first wave. *BMJ Open*. 2021; 11(5):1-9.
  14. Norouzadeh R, Abbasinia M, Tayebi Z, et al. Experiences of patients with COVID-19 admitted to the intensive care units: a qualitative study. *J Patient Exp*. 2021;8:237437352110073. doi:[10.1177/23743735211007359](https://doi.org/10.1177/23743735211007359)
  15. Sun N, Wei L, Wang H, et al. Qualitative study of the psychological experience of COVID-19 patients during hospitalization. *J Affect Disord*. 2021;278:15-22. doi:[10.1016/j.jad.2020.08.040](https://doi.org/10.1016/j.jad.2020.08.040)
  16. Leigh JP, Kemp LG, de Grood C, et al. A qualitative study of physician perceptions and experiences of caring for critically ill patients in the context of resource strain during the first wave of the COVID-19 pandemic. *BMC Health Serv Res*. 2021;21(1):374.
  17. Bennett P, Noble S, Johnston S, Jones D, Hunter R. COVID-19 confessions: a qualitative exploration of healthcare workers' experiences of working with COVID-19. *BMJ Open*. 2020;10(12):1-7.
  18. Montgomery CM, Humphreys S, McCulloch C, Docherty A, Sturdy S, Pattison N. Critical care work during COVID-19: a sociological analysis of staff experiences. *SSRN Electron J*. 2021;11:1-18.
  19. Bartoli D, Trotta F, Simeone S, et al. The lived experiences of family members of Covid-19 patients admitted to intensive care unit: a phenomenological study. *Heart Lung*. 2021;50:926-932. doi:[10.1016/j.hrtlng.2021.08.002](https://doi.org/10.1016/j.hrtlng.2021.08.002)
  20. Chen C, Wittenberg E, Sullivan SS, Lorenz RA, Chang YP. The experiences of family members of ventilated COVID-19 patients in the intensive care unit: a qualitative study. *Am J Hospice Palliat Med*. 2021;38(7):869-876.
  21. Klop HT, Nasori M, Klinge TW, et al. Family support on intensive care units during the COVID-19 pandemic: a qualitative evaluation study into experiences of relatives. *BMC Health Serv Res*. 2021;21(1):1-12.
  22. Major ME, Van Nes F, Ramaekers S, Engelbert RHH, Van Der Schaaf M. Survivors of critical illness and their relatives a qualitative study on hospital discharge experience. *Ann Am Thorac Soc*. 2019;16(11):1405-1413.
  23. Gonçalves AC, Leckie T, Hunter A, et al. Technology supported rehabilitation for patients of critical illness caused by COVID-19: a protocol for a mixed-methods feasibility study. *Int J Therapy Rehabil*. 2020; 27(10):1-9.
  24. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.
  25. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Mental Health Mental Health Serv Res*. 2013;42:1-12.
  26. Valerio MA, Rodriguez N, Winkler P, et al. Comparing two sampling methods to engage hard-to-reach communities in research priority setting. *BMC Med Res Methodol*. 2016;16(1):1-11.
  27. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol*. 2020;00(00):1-25. doi:[10.1080/14780887.2020.1769238](https://doi.org/10.1080/14780887.2020.1769238)
  28. Birt L, Scott S, Cavers D, Campbell C, Walter F. Member checking: a tool to enhance trustworthiness or merely a nod to validation? *Qual Health Res*. 2016;26:1802-1811.
  29. Kaplan B. Revisiting health information technology ethical, legal, and social issues and evaluation: telehealth/telemedicine and COVID-19. *Int J Med Inform*. 2020;143:1-17.
  30. Corner EJ, Murray EJ, Brett SJ. Qualitative, grounded theory exploration of patients' experience of early mobilisation, rehabilitation and recovery after critical illness. *BMJ Open*. 2019;9(2):e026348.
  31. Lopez-Soto C, Bates E, Anderson C, et al. The role of a liaison team in ICU family communication during the COVID 19 pandemic. *J Pain Symptom Manage*. 2021;62(3):e112-e119. doi:[10.1016/j.jpainsymman.2021.04.008](https://doi.org/10.1016/j.jpainsymman.2021.04.008)
  32. Liu Q, Luo D, Haase JE, et al. The experiences of health-care providers during the COVID-19 crisis in China: a qualitative study. *Lancet Glob Health*. 2020;8(6):e790-e798.
  33. Page P, Simpson A, Reynolds L. Bearing witness and being bounded: the experiences of nurses in adult critical care in relation to the survivorship needs of patients and families. *J Clin Nurs*. 2019;28:3210-3221.
  34. Deimling GT, Bowman KF, Wagner LJ. Cancer survivorship and identity among long-term survivors. *Cancer Invest*. 2007;25(8):758-765.
  35. Little M, Paul K, Jordens CFC, Sayers EJ. Survivorship and discourses of identity. *Psychooncology*. 2002;11(2):170-178.
  36. Kean S, Salisbury LG, Rattray J, Walsh TS, Huby G, Ramsay P. 'Intensive care unit survivorship' - a constructivist grounded theory of surviving critical illness. *J Clin Nurs*. 2017;26(19-20):3111-3124.
  37. Prescott HC, Iwashyna TJ, Blackwood B, et al. Understanding and enhancing sepsis survivorship priorities for research and practice. *Am J Respir Crit Care Med*. 2019;200(8):972-981.
  38. Kean S, Donaghy E, Bancroft A, Clegg G, Rodgers S. Theorising survivorship after intensive care: a systematic review of patient and family experiences. *J Clin Nurs*. 2021;30(17-18):2584-2610.
  39. Haines K, McPeake J, Hibbert E, et al. Enablers and barriers to implementing ICU follow-up clinics and peer support groups following critical illness: the thrive collaboratives. *Crit Care Med*. 2019;47(9): 1194-1200.
  40. Sevin CM, Bloom SL, Jackson JC, Wang L, Wesley Ely E, Stollings JL. Comprehensive care of ICU survivors: development and implementation of an ICU recovery center. *J Crit Care*. 2018;46:141-148.

## SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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