**Insights into recovery from severe COVID-19: triangulation of stories from survivors, relatives and professionals**

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**ABSTRACT**

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

DESIGN, SETTING, AND PARTICIPANTS: In-depth qualitative interviews were conducted with three stakeholder groups: survivors of severe COVID-19 of the first wave of the pandemic, relatives or friends and professionals involved in their care. Participants were recruited from five acute hospitals in England and interviewed remotely, with data analysed following thematic analysis.

FINDINGS: 23 participants were included (12 professionals, 6 survivors and 5 relatives). Their collective narratives are presented through three main themes: (1) Deteriorating fast: a downhill journey from symptom onset to critical care; (2) Facing a new virus in hospital and; (3) Returning home as a survivor, maintaining normality and recovering slowly.

CONCLUSIONS AND RELEVANCE: This study triangulating experiences of critical care from the first wave of the pandemic highlights challenges in accessing care and communications between patients, staff and relatives. Following hospital discharge, patients adopted a ‘survivor identity’ to cope with the slow recovery process. The concept of survivorship in this patient group may be beneficial to promote and explore further.

**INTRODUCTION**

By the end of April 2021, more than 400 000 people in the UK had required a hospital admission due to COVID-19[[1]](#footnote-1). Of those Y are known to have survived an admission to critical care and started their journeys towards recovery. Each wave of infection is inevitably followed by a wave of survivors of critical illness with potentially high rehabilitation needs. Understanding the process of recovery and rehabilitation post critical illness due to COVID-19 is therefore urgently needed.

The sequelae of critical illnesses are well known [ref], but the optimal recovery pathway is yet to be defined [ref]. For survivors of critical illness due to COVID-19, as a novel virus, uncertainties regarding recovery and rehabilitation are even greater. Further, their pathway of recovery and access to health care has and will be altered by social distancing measures and additional pressures on health and social care during the pandemic.

In this context the experiences those who survived severe COVID-19 in the first wave of the pandemic in the UK, as well as their relatives and the professionals involved in their care, can provide invaluable insight into the trajectories of recovery and inform how best support the rehabilitation process of those surviving a severe COVID-19 infection in the future.

To date reports have explored experiences of health care professionals and survivors during the COVID-19 pandemic [refs]. Triangulation of experiences and views on recovery, rehabilitation and understanding have not been explored. Experiences of all key stakeholders involved are essential to plan delivery of rehabilitation.

Therefore, the present study aims to gain in-depth understanding of the experiences of recovery from the perspective of survivors of severe COVID-19, their relatives and professionals involved in their care.

**METHODS**

**Study 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 as a result of COVID-19 up to one year following hospital discharge. As part of this larger study (reference to our protocol), we conducted in-depth qualitative interviews with three groups of stakeholders: survivors, their relatives and health professionals involved in their care 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. Future qualitative work will be conducted to explore the rehabilitation process at one year post discharge. The present study followed the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007).

**Sampling and recruitment**

Participants were recruited between May and July of 2020. Detailed inclusion and exclusion criteria can be found in the study protocol (ref to our protocol). Health professionals were recruited in all hospital sites through the participant information sheet being shared with team leads of doctors, nurses and therapists working with survivors of critical illness due to COVID-19. A maximum variation sample strategy (ref) was used to include professionals of a variety of clinical backgrounds and hospital services. Survivors included in the main study were invited to be interviewed, also following a maximum variation strategy accounting for age, mode of mechanical ventilation and hospital length of stay. A snowball recruitment strategy (ref) 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 a joint or separate interview, according to their preference. The sample size was determined, not on data saturation, but on reaching a variety of demographic characteristics of all participants. Recruitment will continue for the second part of the interviews at one year post hospital discharge.

**Interview procedures**

We conducted semi-structed interviews following a topic guide, developed by ACG and CK, which covered the participants’ experience of illness due to COVID-19 and probed their narratives of going through or supporting recovery and rehabilitation post admission to critical care. The topic guides to each of the stakeholder interviews are available on request.

Two dyads (survivor-relative) were interviewed together. All other participants were interviewed on a one-to-one basis by ACG, by telephone or videocall. ACG is a researcher with experience in conducting qualitative interviews, and a clinical physiotherapist who worked in one of the acute hospitals included in this study prior to the beginning of the COVID-19 pandemic.

**Analysis**

The interviews were audio recorded, transcribed verbatim and analysed following principles of thematic analysis (Carolina to check latest paper from Braun and Clark and add ref and details here). NVivo (version xxx) was used to aid data organisation. All transcripts were initially coded by ACG. A subset of six interviews was also coded by AW and CK and the codes then compared and discussed by the three authors, in order to allow in-depth analytical discussions of the data. After these analytical discussions, the initial codes were merged into higher level codes and themes, developed by ACG, with regular discussions with AW and CK, and supported by the use of a reflective diary and constant references back to the original data set. Once preliminary themes were determined, member checking (ref) was conducted with one participant from each stakeholder group, which further developed the final thematic map (figure 1).

**Ethical approval**

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 consent was obtained from all participants.

**FINDINGS**

**Sample characterisation**

A total of 23 participants (12 professionals, six survivors and five relatives), across five different acute hospitals were interviewed. Table 1 presents further detail on characteristics of the participants. The interviews had a mean duration of 57 minutes (ranging from 38.43 to 72.22 minutes).

*Table 1 - sample characterisation*

|  |  |
| --- | --- |
| **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%) |
| Medical doctor | 3 (25%) |
| Nurse | 2 (16%) |
| Speech and language therapist | 1 (8%) |
| Dietitian | 2 (16%) |
| Years of experience | 13.8 (±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%) |
| Black, Asian, and minority ethnic | 1 (17%) |
| Previously in paid employment | 3 (50%) |
|  |  |
| **Role: relative or friend (n=5)** | **N (%) or Mean (±SD)** |
| Gender (Male) | 0 (0%) |
| Age | 59 (± 8.7) |
| Relationship to the survivor |  |
| Spouse or partner | 3 (60%) |
| Child | 1 (20%) |
| Friend | 1 (20%) |

**Experiences of recovery from the perspectives of survivors, relatives and professionals**

Three themes can explain how each stakeholder group described their experience of recovery and rehabilitation (Figure 1). The first theme, “Deteriorating fast: a downhill journey from initial symptoms to critical care”, sets the scene by bringing into light how survivors quickly deteriorated and became critically ill. The second theme “Facing a new virus in hospital” illustrates recovery in 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.

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Deteriorating fast: a downhill journey from initial symptoms to critical care.

Returning home as a survivor, maintain normality and recovering slowly

Facing a new virus in hospital

Theme 1. Deteriorating fast: a downhill journey from initial symptoms to critical care

Survivors had significant memory gaps regarding the period of time between symptom onset and their 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 headlights - survivors and relatives faced resistance in accessing care as symptoms deteriorated. Relatives of those infected 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 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 explain 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 wouldn’t 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]*

Theme 2. Facing a new virus in hospital

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’. (ref)*

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 .’ (ref)*

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.

*‘…it is very, very tiring. That’s all I would say. (…) It is not something you had encountered before, and being younger you (…) you are really like: “oh, these guys have so much more life” I think that amount… an investment for that amount of time would make doing any more surges quite hard to manage [ref]*

Despite the knowledge that there was no flexibility for staffing numbers, 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.

*‘We were trying to just do whatever we could to assist each other, when we knew somebody was having a bad day: ok I will just step out slightly more out of what we normally do, just to give them a little bit of help. And vice versa.’ {ref}*

In addition to the peer support within hospital staff, professionals described other 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.’ (ref)*

**Theme 3. Returning home as a survivor, maintaining normality and recovering slowly**

As described in theme 2, hospitals became remote, isolated places during the pandemic. Leaving the hospital to return home was an important milestone to 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… and that was quite… that was very different and quite difficult to… to manage sometimes because people would be like, you can put someone in a short-term placement, who could be home within three days (Occupational therapist, Female)”*

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

The interviewed relatives described receiving the news of their loved one’s discharge with huge relief. But some felt ill prepared to care for their loved one 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 that 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).*

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

*“It would have been nice if… 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” (Daughter, 50 years old).*

The burden of the recovery process was increased by the severity of the sequelae (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 services.

*“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).*

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, being 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 aaa 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 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, but also 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. And aaa I don’t deal with that very well actually” (Survivor, Male, 59 years old).*

**DISCUSSION**

To our knowledge, this is the first study to triangulate views of survivors, their relatives and the professionals involved in their care on the recovery process after admission to critical care due to severe COVID-19. 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 critically ill survivors are slowly recovering, towards a reframed “survivor identity”.

The narrative of our triangulated voices fell into three themes during the journey from illness to recovery. Challenges in accessing care in the beginning of the pandemic, reported by survivors and relatives in the first theme, highlight the significant problems which continue to be experienced worldwide. A literature review by Kaplan (2020) highlighted how the use of telecare expanded rapidly during the pandemic, providing an opportunity to evaluate these forms of health care. Our findings from the experience of the first wave suggest shortcomings in remote triage of patients, though further study could elucidate whether these have subsequently been addressed.

Communication, in theme two, was a key aspect all stakeholders wished to see improved and maximised in hospital. Having a loved one on the bedside is a common first memory of critical care survivors (Corner et al., 2019). 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 (Su et al 2021; Norouzadeh et al., 2021). Maximising 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 (Liu et al., 2020; Leigh et al 21; Bennett et al., 2020), adding to the body of evidence documenting the efforts of those on the frontline of the pandemic.

Lastly, the third theme addressed the returning home and the assumed “survivor identity”. The concept of “survivor identity” is well established in the cancer literature (refs) and it has recently been explored in critical care survivors in general (Corner et al., 2019 and Kean et al., 2016). Kean et al., 2016 describe “survivorship” as a different concept to “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. Interestingly, the participants in this study told narratives of “survivorship”, as their recovery is yet to be completed. Corner et al., 2019 theorised the rehabilitation journeys post critical illness, as a process of “recalibration” for survivors, in which they adjust their current and futures 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, as professionals were not able to guide survivors regarding what to expect and relatives might have struggle 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 been linked to better mental health as well as engagement in health promotion activities (Deimling et al., 2007). Survivorship in severe COVID-19 might therefore be an important concept to promote by health professionals and in public health messages.

Strengths and limitations

Interprofessional teamwork and active engagement of relatives has been reported as essential to the rehabilitation of critical care survivors (Heines et al 2019; Savin et al., 2018). The present study, through its triangulated design, 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. The data presented provides valuable insight into the complex process of 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. Coincidently, all survivors chose to invite a female relatives or friends 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 at 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 a strength of this study, only professionals from acute hospitals were included. In order to minimise this limitation, some of the included professionals did outreach work with survivors in the community. Future work should include professionals from community settings, involved in supporting more closely the rehabilitation of survivors of severe COVID-19 post hospital discharge.

**CONCLUSION**.

This multi-centre study of stories of survival from the first wave of the COVID-19 pandemic in the UK, found challenges in accessing care and maintaining communication between the hospital and the outside world. Three months following hospital discharge, survivors had adopted a survivor identity to help work towards their recovery. The next stage of this project will include a longitudinal follow up a year following discharge, to better map the recovery process of survivors of severe COVID-19.

1. https://coronavirus.data.gov.uk/details/cases [↑](#footnote-ref-1)