**Title**

Patients’ perspectives of recovery after COVID-19 critical illness; an interview study

**Abstract**

Background

Critical illness is a traumatic experience, often resulting in post intensive care syndrome, affecting people’s physical, psychological, emotional, and social well-being. The early recovery period is associated with increased risk, negatively impacting longer-term outcomes.

Aims

The aims of this study were to understand the recovery and rehabilitation needs of people who survive a COVID-19 critical illness. Objectives were to:

* Describe survivors’ experiences of COVID-19 critical illness
* Identify survivors' perspectives on the support required to optimise rehabilitation and recovery
* Determine the extent to which findings align with those of other critical illnesses survivors.

Design and Methods

An exploratory descriptive qualitative interview study with 20 survivors of COVID-19 critical illness from two community-based healthcare settings in London, England. Data collection took place September 2020-April 2021, at least one month after hospital discharge by telephone or virtual platform. Data were subjected to a standard process of thematic analysis and mapped to the three core concepts of self-determination theory: autonomy, competence and relatedness.

Findings

Three key themes emerged: traumatic experience, human connection and navigating a complex system. Participants described how societal restrictions, fear and communication problems caused by the pandemic added to their trauma and the challenge of recovery. The importance of positive human connections, timely information and support to navigate the system was emphasised.

Conclusions

Whilst findings to some extent mirror those of other qualitative pre-pandemic studies, our findings highlight how the uncertainty and instability caused by the pandemic adds to the challenge of recovery affecting all core concepts of self-determination (autonomy, competence, relatedness).

Relevance to clinical practice

Understanding survivors’ perspectives of rehabilitation needs following COVID-19 critical illness is vital to delivery safe, high-quality care. To optimise chances of effective recovery, survivors desire a specialist, co-ordinated and personalised recovery pathway, which reflects humanised care. This should be considered when planning future service provision.**Introduction**

Despite mortality rates of approximately 40% for those admitted to an intensive care unit (ICU) with COVID-19 during the height of the pandemic in the United Kingdom (UK),1 there are also now an unprecedented number of survivors.2 To prioritise patient-centred rehabilitation and recovery interventions for these survivors, there is an urgent need to understand more fully the consequences of having a COVID-19 critical illness.3

**Background**

For many people, COVID-19 is a mild condition. However, for those who develop more severe illness, advanced ventilatory support with, or without, admission to an ICU may be required. Worldwide, among all hospitalised patients with COVID-19, approximately 26-32% have required ICU admission,4 although these numbers have fallen since the roll-out of the vaccination programme. Newer variants, such as Omicron are also associated with a lower ICU admission rate than those from earlier in the pandemic.5

Critical illness causes long-lasting physical, cognitive, and psychosocial problems, negatively impacting people’s quality of life; termed post-intensive care syndrome (PICS).6,7,8 Poorer quality of life compared to population norms is repeatedly identified in survivors of critical illness for up to five years, with both physical and mental health domains compromised.9 Post-traumatic stress disorder (PTSD) also compromises physical recovery,10,11 meaning people are less likely to return to work and require increased health and social care services.12,13

A meta-synthesis by Baumgarten et al. highlights ICU as a place, which makes people feel vulnerable, isolated, exhausted, and overly dependent on others.14 Corner et al. also note that the early rehabilitation period is associated with increased risk of subsequent psychological distress, negatively impacting longer-term recovery.15

The need to improve the health and wellbeing of people recovering from a critical illness is emphasised worldwide.6,16,17 National guidance has been produced by the National Institute of Health and Care Excellence (NICE)18,19 and professional bodies20 and guidance specifically on rehabilitation after COVID-19 critical illness has also been published.21

Whilst outcome data from COVID-19 such as mortality are starting to emerge,1,22,23 COVID-19 survivors’ personal experiences are an important, but under researched area. Drawing parallels with other ICU survivors’ experiences has intuitive resonance. However, patients admitted to ICU with COVID-19 were younger, had fewer prior comorbidities, and were more likely to be male.24 Those from a black or minority ethnic group and those with a higher body mass index were also more severely affected.25 Alongside these demographic factors, the health and social care system had to be remodelled, wide societal restrictions were in place and concern about the perceived or actual risk of COVID-19 to family, friends, and healthcare staff was evident. Prati et al. note that the impact on the mental health of the general population varied. However, the effect of these factors on people’s recovery after ICU also needs consideration.26

**Study aims**

The aims of this study were to understand the recovery and rehabilitation needs of people who survive a COVID-19 critical illness. Objectives were to:

* Describe survivors’ experiences of COVID-19 critical illness
* Identify survivors' perspectives on the support required to optimise rehabilitation and recovery
* Determine the extent to which findings align with those of other critical illnesses survivors.

**Design and Methods**

An exploratory descriptive qualitative methodology27 was employed to gain understanding of people’s subjective realities.28 Approval was granted from the Health Research Authority (285898) and the Institute of Health and Social Care ethics committee at XXX (ETH1920-0176).

***Setting, Sample and Recruitment***

In partnership with local secondary care hospitals, we recruited a sample of COVID-19 survivors (See Box I) from two community healthcare organisations in England. Purposive sampling, with an aim to achieve maximum variation, was chosen to ensure the sample were most likely to answer the research question.29 We also incorporated snowballing, whereby those who took part were encouraged to promote the study to others.

Box 1: Inclusion and exclusion criteria

Virtual meetings with key healthcare staff including two patient experience facilitators helped identify potential participants, who were then screened by a nominated staff member at each data collection site. All those who met the inclusion criteria were invited to participate via an information sheet given to them in person whilst they were still in a community bed. Those already discharged were sent an invitation by post. Potential participants directly registered their interest via telephone, email, or the nominated staff member. All participants were sent a letter of thanks at the end of the study.

Recruitment took place September 2020 to April 2021. Most participants contracted COVID-19 during wave one of the UK pandemic, March-May 2020,30 although four participants fell ill in the first quarter of 2021 (see table 1).

***Data collection methods and tools***

Data were collected using one-to-one audio-recorded semi structured interviews, lasting no more than one hour. All interviews took place at least one month after discharge home. Interviews took place by telephone or using a secure virtual platform (such as Microsoft Teams or Zoom), according to participants’ preference.

Researchers conducted all interviews using a topic guide (supplementary file 1). Questions were informed by published literature, reviewed by our patient representative, and the tool was piloted in the first interview. After establishing key demographics (age, sex, marital status, ethnicity, place of residence, co-morbidities, date of illness) open questions were divided into three sections: experiences of COVID-19 critical illness; impact of COVID-19; mitigating factors. Participants were invited to add other information they felt relevant before the close of the interview.

***Data analysis***

Anonymised and verbatim-transcribed interview data were uploaded to NVIVO13.  Interview notes from researchers were added to transcripts. Transcripts were not returned to participants as there is little evidence that this improves research credibility.31

Data underwent a standard process of thematic analysis as described by Braun & Clark.32 Analysis started with an inductive approach so that the voice of the participants was foremost. An initial coding framework was developed by both research assistants (AJ/NM) independently open coding two transcripts. This resulted in an initial 17 codes, with agreed definitions, that were subsequently used to review all other transcripts. As additional codes were identified, an iterative process was used whereby previous transcripts were re-reviewed. Each research assistant coded transcripts of interviews conducted by the other. Meetings between both research assistants were held weekly to discuss and agree codes. Draft themes and subthemes were reviewed by the whole project team and a consensus approach was used to resolve any differences in interpretation and determine final themes (Figure 1).

A deductive process whereby data were mapped against a conceptual framework was then undertaken to assess the extent to which findings were congruent with those from pre-pandemic ICU survivors, reported by Corner et al.15 focusing on the three core concepts of self-determination theory: autonomy, competence, and relatedness.33 Findings from Corner et al.’s study showed that critical illness negatively impacts patients’ sense of autonomy, competence, and relatedness, which in turn can reduce the motivation required to effectively engage in rehabilitation.15 This study sought to determine the degree to which this is further affected by the unique features of COVID-19.

***Rigour: Research team and reflexivity***

The study was registered on the COVID-19 Mental Health Studies Register: <https://www.maudsleybrc.nihr.ac.uk/research/covid-19-studies/> and is reported in line with the consolidated criteria for reporting qualitative research (COREQ) 32 item checklist.34 Led by a Professor in critical care nursing (SB) the team included experienced clinical-academic nurses, (SB/NT/AJ/MH), midwives (NM) and doctors (HF) from critical and community care and a clinical psychologist (GP). A patient/carer representative with a defined disability and experience as the partner of an ICU survivor (HC) sat on the project steering group and two patient experience facilitators helped promote the study, recruit participants, and disseminate findings (EB/NP). All data collection was overseen by experienced qualitative researchers (NM/SB/NT).

Participants provided informed consent prior to interview. To mitigate the trauma of discussing critical illness experiences, a distress protocol written by our clinical psychologist and patient representative guided our practice. Nursing and midwifery council registered researchers (NM/AJ) conducted all interviews at least one month after hospital discharge, in accordance with best practice.35 Participants were also encouraged to take steps they felt would support them (e.g., having someone with them).

To account for researcher influences on the data, a reflexive diary was kept by all team members.36 All decisions regarding data collection and analysis were discussed and agreed by the whole team and a written record was kept demonstrating transparency, truth, consistency, confirmability and applicability.37

**Findings**

Twenty participants were recruited (see Table 1). Male: female ratio was 1:3. The sample was predominantly white British with a mean age of 61 years (range 48-76). Patient-reported overall length of stay in hospital was on average three months, with half the sample reporting being transferred to a community rehabilitation unit following the acute hospital stay.

Table 1: Sample characteristics

**Themes**

Three key themes emerged: (i) traumatic experience, (ii) human connections and (iii) navigating a complex system; all underpinned by an overarching theme of uncertainty and instability. Figure 1 details the final three themes and subthemes. A list of the initial codes which were amalgamated to produce can be seen in supplementary file 2.

Figure 1: Themes, subthemes and categories

***Traumatic Experience***

Participants described a very traumatic experience, which stayed with them after hospital discharge, negatively affecting their well-being. Participants described an acute awareness of how ill they had been and uncertainty about the chance of survival, leaving them feeling frightened. Even after hospital discharge, participants remained fearful and this impacted on their confidence to resume everyday activities: “*We used to go to the mall where we can sit to eat at the mall just a few people in there, I don’t like to mix with a crowd of people because I’m still scared*” (P5).

The recovery period was a time for much reflection. Hope for the future was expressed, but participants also described a survivors’ guilt, including a struggle to understand why they had been ‘lucky’, particularly if they had risk factors such as obesity or other pre-existing health conditions: “*I think the other really difficult thing for me - I may cry again - is this feeling of survivor's guilt which is huge…It's almost like, 'Why didn't I [die]? What's so special about me?'…Yeah, that's really hard” (P18).*

A key element underpinning fear was the ‘surreal’ surroundings, with the hospital environment described as resembling a ‘science fiction film’: “*I can see myself like waking up at times and see loads of people on the ward all masked up and it was quite frightening, it looked like a science fiction film that I was in*” (P4). Fear was further exacerbated by hearing that hospitals were running out of oxygen with some participants describing having to be transferred to an alternative hospital with oxygen supplies.

Participants described a wide range of post COVID-19 health impacts spanning both physical and mental health. Symptoms reported included pain, breathing difficulties, fatigue (which also affected mobility), memory and other cognitive difficulties, sleeping problems and mental health challenges including anxiety, depression, and symptoms of PTSD. Participants also described the emotional toll that being so acutely unwell had taken on them and their families: “*My daughter walked into the study, I was sat there with my husband, just you know taking it all in and my daughter came in and three of us just broke down crying*” (P17). In some cases, participants’ experiences had also prompted them to discuss their end of life wishes. Highlighting the high number of deaths witnessed, one participant said, “*I had people dying next to me every day. I know the last rights in every language, in every religion going now*” (P14).

Participants’ trauma appeared exacerbated by others’ reactions to their condition. Some described how healthcare staff seemed fearful of treating and caring for them and the lasting impact these feelings of being stigmatised had on their mental wellbeing, deepening their sense of abandonment: “*The consultant came, he didn’t examine me, he stood as far away from me as he possibly could…probably his own fear*…[also] *one person looked at me like I had leprosy...I think that’s had a massive impact on me, a massive impact*” (P17).

Whilst many participants described symptoms of anxiety, depression, or PTSD (in themselves or family members) few had accessed any counselling or psychological support, even when offered. Some had returned to work, but for others this remained uncertain bringing additional financial pressures: “*we’re both nurses…I want to work; I want to go back to work already… I don’t even go for a month off from work [previously] because I don’t take holidays like that*” (P5-wife).

***Human connection***

The importance of human connection was emphasised and the positive difference it made to participants’ perceptions of receiving high quality care. Not everyone had a positive experience. However, where connections with healthcare staff were made, they were highly valued. In particular, acts of kindness, and staff going above and beyond purely clinical duties, made participants feel like they were ‘seen’ and were being cared for as individuals, rather than ‘just’ another COVID patient: “*There was a staff nurse…she bought a card … took me out so I could spend half an hour with my wife... that was just the most memorable instances of lots and lots of very kind things that she did for me*” (P11). Participants described the importance of regular contact with people, regardless of their position in the hospital. Particularly striking examples were given in relation to auxiliary staff such as cleaners, who often engaged in everyday ‘small talk’: “*The cleaner was just, he was phenomenal, every day he come in and talked about anything other than COVID and being ill*.” (P17).

Positive human connections were, however, affected by the need for personal protective equipment (PPE). Whilst staff did their best to overcome the communication challenges PPE posed, it was seen as a barrier to building rapport and trust. During this time, eye contact and touch took on increased importance:

“*Yellow masks like bird beaks, ducks… I said to the lady in the bed next to me, we were giggling, I said ‘oh the ducks have come to take us*” (P6).

“*They write their name across their chest …But that was, it wasn’t easy… I found some of the mask wearers more difficult to understand…* *We've not for the last year been able to touch people…just the hold of the hand and the look in the eye*” (P17).

The quality and nature of communication was also affected by the social distancing rules and the ban on hospital visiting. The subsequent reliance on virtual communication was, overall, perceived as a good thing, which enabled participants to maintain contact with family and friends and facilitated engagement in social activities, helping retain their sense of being connected beings. However, some participants experienced a sense of pressure to keep up with responding to messages updating on their condition and treatment:

“*Now, they're doing FaceTime on iPads, aren't they? They weren't at that time….so I didn't have any contact…I remember the nurse saying, 'I'll bring your phone over.'… I remember hearing [X’s] voice…I'm so sorry, I'm going to get upset now…I didn't understand why they weren't there*” (P18).

“*People text you and go, how are you? I keep saying I'm okay but because I want, I don’t want to say, actually I'm feeling SH1T*” (P17).

***Navigating a complex system***

No uniform package of discharge care was evident, with provision seemingly dependent on where people lived. Some participants considered these disparities reflective of a National Health Service (NHS) in a state of crisis. Staff were described as doing “*the best they could*” (P16) in extremely challenging circumstances. However, participants expressed concern about the speed with which discharge from the acute setting occurred, particularly during the early pandemic period: “*I was really scared that something dramatic would go wrong at home…So yeah that, it was a huge fear of going home and dealing with it myself*” (P1).

Perceptions of after care and support varied depending on how well people felt their needs were met, the mode of service delivery, and their home living status. Unfortunately, however, some participants described feeling ‘neglected’ and ‘left to get on with it’: “*I had the district nurse come out the day after discharge…she just basically said, we’re not coming out to see patients...the physiotherapist didn’t come and see me, she spoke to me on the phone twice and sent me exercises to do…my GP has been useless…just been left to get on with it, and all you hear is, we don’t know enough about COVID to know what to do.*” (P1).

Participants who had the opportunity to go to a rehabilitation unit before returning home reported varying experiences. For some, these units were seen as an important bridge to home and described as a space, and the support, to aid adjustment back to everyday life; to begin the journey of rebuilding self-confidence: “*It was just a self-boosting thing for me…it was like an easing back into life…* *the esteem building, like confidence building again…I don’t know if I could have done that coming straight home, I really don’t*” (P4). However, not everyone had the opportunity to go to a rehabilitation unit and experiences were not always as positive as expected. Less positive experiences focused on inadequate provision of therapy services, faciliaties such as gyms being closed 'because of covid', being far from home and poor communication. Some participants who became ill later in the pandemic had been followed up in COVID-19 specific clinics, but this was not true for everyone. Follow up care was also affected by cancellation of elective services and the mode of follow up service delivery. Virtual appointments, particularly for therapy services were often perceived as inferior to face to face sessions, leading those with financial means to privately fund access to face-to-face support.

Participants’ own mindset and the degree to which they received encouragement by healthcare staff, family and friends was perceived to be critical to recovery; to their ability to keep going and to keep positive. Friends and family provided practical everyday help with tasks such as cooking meals, making phone calls and ongoing emotional support and love, and participants expressed concern for those without access to these support mechanisms:

“*C’est la vie is whether you get help, or you don’t get help. You adapt and you conquer*” (P19).

“*… they wouldn't let me give up* *… I said I couldn't do this, and I couldn't do that, and a couple of the nurses said, 'Oh yes you can*…*You've got to have a lot of support. If someone lived on their own, they would fold up, I'll tell you*” (P20).

The desire to exercise autonomy and control over their recovery was clearly evident from participants’ interviews. However, this took up a lot of time and energy at a point when people were feeling physically and mentally weak. Participants described feeling overwhelmed with the task of managing their rehabilitation, for example making phone calls and chasing appointments. Participants expressed a need for someone to help them navigate through what was an otherwise complex and frustrating system to help reduce the burden on them and their family: “*It’s nice to have that regular person that you’re talking to so, I don’t have to explain it again and again…she’s aware of what went on and yeah, like I say the first thing is, ‘How are you doing now? How are you feeling?*” (P13).

Participants described a range of factors they perceived helped their recovery and rehabilitation. These included religion and spirituality, being able to re-engage in normal social activities and being able to go outside. However, the pandemic meant that these things were not always possible or were more difficult: *“I need fresh air more…* *I want to go fishing. I want to get out. The trouble is with Covid, you can't even go abroad for a holiday in the sun, can you*” (P20). Self-help support groups were also viewed as beneficial, offering the opportunity to share and normalise experiences. These groups were seen as particularly helpful to filling the gaps in information provided by the healthcare team about what to expect during recovery in terms of both symptoms and length of recovery period: “*You know you’re not going crazy, what you’re feeling is real, there’s other people out there feeling the same as you*” (P1).

The importance of honest, clear, and timely information, tailored to individual circumstances was viewed as critical to helping understand their experience and to support their ongoing recovery. In particular, knowing the sequence of treatment and events was considered important to their ability to construct an account of illness and contextualise their own recovery: “*It was important to know the day I woke up, the day they stopped sedation, they day I spoke to my partner for the first time again…not so much the treatment but those three things were really important to me*” (P1).

A high degree of uncertainty was expressed about what ongoing care would or should look like and some participants described how a lack of information about what symptoms to expect during recovery exacerbated their fear of being discharged from hospital: “*My hair came out in absolute clumps for about a month…it was only one of my GP’s that said to me… ‘it’s quite normal that this happens’ but you know just little things that I would like to have known*” (P15). Overall, participants described feeling frustrated, with some experiencing a clear lack of signposting to services: “*You should know where to signpost us, you should know where to be able to give us that help and support… but nothing, we’ve had to do it ourselves and wing it…there should be no difference in COVID recovery to any other recovery provision…having designated teams that you know in your area you can contact for that support, and not being sent out leaflets of how to do things.*” (P1).

The following quote encapsulates a view expressed by many participants: “*People just need to understand that it's not just as simple as surviving and being okay*” (P18).

**Discussion**

Whilst our findings to some extent mirror those of other qualitative pre-pandemic studies exploring critical illness experiences, the uncertainty and instability created by the worldwide COVID-19 pandemic added to the challenge of successful rehabilitation and recovery.

According to self-determination theory, effective rehabilitation and recovery can only be fully achieved when the core concepts of autonomy (the ability to be in control of oneself), competence (the ability to manage a situation) and relatedness (the ability to have an emotional connection with others) are met.33 Our findings, based on the experiences of people recovering from COVID-19 support those of Corner et al.,15 highlighting that critical illness negatively affects all these concepts, both during and after the in-hospital period.

Our COVID-19 ICU survivors expressed a strong fear of death, combined with substantial concern about the risk of passing the virus to others, affecting their autonomy, competence, and relatedness. Similar to the findings of Corner et al.,15 human connection emerged as a critical component of effective care and a likely precursor to people’s successful recovery after discharge. Effective human connections were, however, negatively affected by the communication challenges incurred due to the need for PPE, visiting restrictions and the fearful or negative attitudes of some health and social care staff. The isolation previously reported by ICU survivors appears exacerbated for those recovering from COVID-19, especially with the stigmatisation of some groups, such as those with obesity. Our findings resonate with a powerful quote from Dr Maya Angelou: "*People will forget what you said, people will forget what you did, but people will never forget how you made them feel*"(mayaangelo.com).

Any perceived dehumanisation of care is likely to increase the risk of post-traumatic stress symptoms and add to the post critical illness health burden.3 Data supporting longer term mental health impacts is still in its infancy. However, Morin et al.23 reported anxiety (23%), depression (18%), and PTSD (7%) in 94 patients admitted to ICU post COVID-19 four months after discharge. Huang et al.22 also reported an increased risk of anxiety and depression for those admitted to ICU in Wuhan, China, at the six month follow up point. Additionally, Parker et al.1 reported that 20% (*n*=36) of patients had clinically significant anxiety and depression symptoms and 57% clinically significant post-traumatic stress symptoms approximately 2-3 months after hospital discharge. The effects of the COVID-19 pandemic are also likely to exacerbate patients’ delirium and increase the risk of long-term cognitive impairment.38 Furthermore, our findings and those from other COVID-19 studies1,22,23 support the frequent incapacitating problems of weakness and fatigue highlighted in non-COVID-19 studies, which compound the problem.39

During COVID-19, digital technology, such as iPads for virtual visiting and online platforms for follow up appointments became important mechanisms by which communication was sustained. Data from a multi-centre survey by Rose et al.40 support the role of virtual visiting in patient recovery and staff morale, whilst other authors suggest virtual care systems can improve inclusion of vulnerable populations.1 However, our findings and those from studies with other population groups41 suggest that, whilst digital resources certainly are valued by some, they may not suit everyone and may add to anxieties, meaning that improvements in inclusivity are not achieved.

Our findings highlight the challenges COVID-19 survivors and their families faced trying to navigate the post hospital discharge pathway, with inadequate access to post-ICU follow-up and rehabilitation services leading to an inconsistent and less than ideal experience for many survivors. This added to the burden of recovery both for the patient and their family. Whilst the burden of care placed on family members of ICU survivors is also reported in the pre-pandemic literature,42 this has been exacerbated during COVID-19 due to systems being overwhelmed, staff redeployment and the worldwide shortage of health and social care professionals.3 Psychological support was offered to many of our participants, but only few accepted, with suggestion that the offer was often poorly timed or not sufficiently focused on their needs, a problem also identified in previous studies.42

**Limitations**

Whilst we met our target sample size, the findings of this study are unlikely to reflect those of all COVID-19 survivors who required ICU admission. Our data were collected at different timepoints during the pandemic and the vaccination programme, and this may account for different experiences as COVID-19 has become normalised in society. Recall bias may also have affected some of the narratives, although this is more of an issue after one year.43,44 All our participants were interviewed within six months of their hospital admission.

Although our sample were self-selecting, demographic details in table 1 support that we achieved our aim of maximum variations sampling, with regard age, sex, length of hospital stay, experience of rehabilitation units and degree of critical illness. We acknowledge, however, that not all patients diagnosed with COVID-19 during the peak of the pandemic had access to an ICU bed and our findings do not represent their experiences or ongoing needs.

**Implications for practice**

Societal uncertainty and instability caused by the pandemic underpins the traumatic experiences of COVID-19 survivors, negatively affecting recovery. These factors must be considered when planning future service provision. COVID-19 ICU survivors require a specialist, co-ordinated and personalised recovery pathway focused on the patient and family. Tailored discharge processes, which reflect humanised care should ensure people leave hospital at the right time, go to the right place, and receive specialist community-based support appropriate to their needs to minimise the risk of readmission.

Effective critical care rehabilitation requires a coordinated and comprehensive approach, a responsibility shared between secondary and primary care teams.45 Hosey and Needham highlight the importance of collaboration between the fields of critical care and rehabilitation to address the significant need that continues to grow,38 with some evidence of this now in existence. Our findings suggest that a care navigation role, similar to that often taken on by families and described by Health Education England (<https://www.hee.nhs.uk/our-work/care-navigation>), may be even more important for ICU survivors of COVID-19. In line with previous research,42,45 the importance of providing patients and their families with timely, accurate and honest information delivered in a language understandable by all is also emphasised.

**Research recommendations**

Further qualitative research to better understand the needs of COVID-19 ICU survivors and their family members is urgently needed. Current work by THIS Institute, capturing ICU survivors and family members stories since the pandemic in the UK will hopefully generate learning to improve future experiences. <https://www.thisinstitute.cam.ac.uk/research-projects/covid-19-intensive-care-patient-experiences/>. It is also hoped this will provide further understanding about what methods can be most effectively deployed to support recovery and return to work. The additional collection of family members’ experiences and perspectives is important, recognising the impact that any critical illness has on the wider family unit.

**Conclusion**

This study sought to understand the recovery and rehabilitation needs of COVID-19 ICU survivors based on their narrated experiences. To our knowledge this is the first published qualitative study to do this. The uncertainty and instability caused by the pandemic, which added to the challenge of recovery, must be considered when planning future service provision. These survivors require a specialist, co-ordinated and personalised recovery pathway, which reflects humanised care if they are to achieve the core concepts of self-determination (autonomy, competence, relatedness) and optimise chances of effective recovery.

**Keywords:** Critical illness; COVID-19; Rehabilitation; Qualitative; Interviews

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**Impacts**

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| --- |
| **What is known about the topic**   * Critical illness is a traumatic experience leaving people with long lasting physical, psychological, social and emotional problems, which negatively affect their quality of life   **What this paper adds**   * Stresses the importance of human connections and describes how societal restrictions, fear and uncertainty caused by the pandemic add to the challenge of recovery after critical illness * Highlights the need to provide survivors with a specialist, co-ordinated and personalised recovery pathway, which reflects humanised care to optimise chances of effective recovery |

**Tables and Boxes**

Box 1: Inclusion and exclusion criteria

|  |
| --- |
| Inclusion criteria   * Adult (>18 years) who received invasive/non-invasive ventilation in any acute hospital-based location following a confirmed diagnosis of COVID-19 * Resident in a bed-based rehabilitation unit or ward at one of the data collection sites OR in own home, but currently or previously under the care of the community rehabilitation team * Access to a telephone or online platform (laptop/computer) * Discharged from an acute hospital setting for at least a month * Able to give informed consent to participate.   Exclusion criteria   * Unable to understand/speak English with no access to an interpreter |

Table 1: Sample characteristics\*

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Participant** | **Age (years)** | **Sex** | **Marital status/Living arrangement** | **Ethnicity** | **Medical History/ Risk factors** | **Work** | **Timeline/**  **Treatment** |
| P1 | 55 | F | Engaged-lives with others | White British | 1 LTC | Health or social care | March/April 2020.  Total admission not known  ICU 22 days.  Tracheostomy |
| P2 | 74 | M | Married | White British | >1 LTC | Retired | March-June 2020.  Total admission 108 days |
| P3 | 65 | M | Married | Asian/ Asian British | 1 LTC | Retired | April-July 2020  Total admission 104 days  ICU 68 days. |
| P4 | 71 | M | Married | White British | No pre-existing conditions | Unknown | March-May 2020  Total admission not known  ICU 30 days |
| P5 | 61 | M | Married | Asian/ Asian British | 1 LTC | Health or social care | April-June 2020  Total admission not known  ICU > 42 days  Tracheostomy  Wife present during interview |
| P6 | 63 | F | Married | White British/ Jewish | 1 LTC | Office-based professional | April 2020  Total admission 9-10 days  ICU for part of stay |
| P7 | 62 | M | Married | White, British Jewish | 1 LTC | Unknown | March 2020.  Total admission approx. 110-115 days  ICU 49 days |
| P8 | 69 | M | Married | White, British | 1 LTC | Transport based profession | March-April 2020  Total admission unknown  ICU 16 days |
| P9 | 71 | M | Married | White, British, Jewish | 1 LTC | Office-based professional | March 2020  Total admission not known  ICU 4-5 days |
| P10 | 48 | M | Divorced-lives alone | Black African | 1 LTC | Unemployed | March 2020  Total admission approx. 150 days  ICU 8 days  Ventilated |
| P11 | 58 | M | Married | White British | 1 LTC | Unknown | March-July 2020  Total admission unknown  ICU stay unknown  Rehab 4-5 weeks |
| P12 | 56 | M | Married | White Other | >1 LTC | Office-based professional | March-July 2020  Total admission107 days.  ICU 16 days |
| P13 | 52 | M | Married | White Irish | 1 LTC | Unknown | December 2020 – January 2021  Total admission unknown  ICU >9 days  Ventilated  Rehab ward before discharge |
| P14 | 63 | M | Divorced | White British | >1 LTC | Office-based professional | March-April 2020:  Total admission: 16 days.  ICU stay 12 days in ICU  CPAP  No rehab |
| P15 | 61 | F | Married | White British | 1 LTC | Transport industries | March-May 2020:  ICU >40 days  Ventilated |
| P16 | 50 | M | Long-term cohabiting relationship | White British | 1 LTC | Transport industries | March-April 2020  Total admission >7 days  ICU 4-5 days  CPAP |
| P17 | 52 | F | Married | White British | None | Health or social care | Jan 2021  Total admission 14 days  ICU stay unknown  CPAP |
| P18 | 52 | F | Single-lives alone | White British | >1 LTC | Education | March 2020  ICU stay and total admission unknown |
| P19 | 60 | M | Married | White British | None | Office-based professional | 2021  ICU > 16 days  Ventilated |
| P20 | 76 | M | Married | White British | 1 LTC | Retired | January – February 2021  Total admission unknown  ICU: >35 days |

F: Female; ICU: Intensive Care Unit; LTC: Long-term condition; M; Male; P: Participant.

\* To protect confidentiality, some patient demographics are reported in overarching groups (e.g., health conditions, employment, social network characteristics).

**Figure Legends**

Figure 1: Themes and subthemes

