

# Evolution in Care Delivery within Critical Illness Recovery Programs during the COVID-19 Pandemic

## A Qualitative Study

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### Abstract

**Rationale:** There are limited data on the impact of the coronavirus disease (COVID-19) pandemic on intensive care unit (ICU) recovery clinic care delivery practices.

**Objectives:** We sought to better understand the patient-level factors affecting ICU recovery clinic care and changing clinical thinking during the COVID-19 pandemic. We also sought to understand how the COVID-19 pandemic sparked innovation within ICU recovery clinics.

**Methods:** A multicenter qualitative study was conducted with ICU recovery clinic interprofessional clinicians involved with the Critical and Acute Illness Recovery Organization (CAIRO) between February and March 2021. Data were collected using semistructured interviews and were analyzed using thematic analysis. Key themes were organized in a working analytical framework.

**Results:** Twenty-nine participants from 15 international sites participated in the study. Participants identified three patient-level key themes that influenced care delivery in ICU recovery programs: 1) social isolation, 2) decreased emotional reserve in patients and families, and 3) substantial social care needs. Changes in ICU recovery clinic care delivery occurred at both the

clinician level (e.g., growing awareness of healthcare disparities and inequities, recognition of financial effects of illness, refinement of communication skills, increased focus on reconstructing the illness narrative) and the practice level (e.g., expansion of care delivery modes, efforts to integrate social care) in response to each of the patient-level themes. Identified gaps in ICU recovery clinic care delivery during the COVID-19 pandemic included a need for multidisciplinary team members, access to care issues (e.g., digital poverty, health insurance coverage, language barriers), and altered family engagement.

**Conclusions:** This study demonstrates that addressing patient-level factors such as efforts to integrate social care, address financial needs, refine provider communication skills (e.g., empathic listening), and enhance focus on reconstructing the illness narrative became important priorities during the ICU recovery clinic visit during the COVID-19 pandemic. We also identified several ongoing gaps in ICU recovery clinic care delivery that highlight the need for interventions focused on the integration of social and clinic services for critical care survivors.

**Keywords:** COVID-19; healthcare delivery; ICU survivors; intensive care unit follow-up clinics; post-intensive care syndrome

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The coronavirus disease (COVID-19) has increased the number of critical illness survivors experiencing post-intensive care syndrome and/or long-term effects of COVID-19, or “long COVID” (1–3). Many hospitals have responded by establishing or expanding intensive care unit (ICU) recovery clinics to meet posthospitalization needs (4–6). ICU recovery clinics use an interprofessional team approach to manage post-ICU problems, including physical weakness, cognitive impairment, neuropsychiatric impairment, and social determinants of health outcomes (e.g., financial toxicity) (4, 7–11). Patients and families have reported that ICU recovery clinics provide continuity of care, improved symptoms, and emotional support (12, 13). However, even before the pandemic, there were many challenges to implementing and sustaining ICU recovery clinics (8, 9, 14–17).

Strategies for overcoming challenges to ICU recovery clinic implementation, growth, and sustainability may benefit from a better understanding of how the COVID-19 pandemic influences all aspects of recovery clinic practice, as momentum and perceived clinical need for these services continue to grow (18). A recent national survey in the United Kingdom provides a glimpse into practice-level changes to ICU recovery services in the context of COVID-19, noting changes to service capacity, mode, and funding (17). However, these results are limited to practice-level changes in one healthcare jurisdiction, leaving the extent of impact of the COVID-19 pandemic on patient and clinician-level changes largely unknown. Identifying patient-level characteristics (e.g., occurring after critical illness) that may be modifiable on the basis of patient-clinician-practice interactions is essential to advance care delivery within ICU recovery clinics.

We sought to better understand the patient-level factors affecting ICU recovery clinic care and changing clinical thinking in the COVID-19 pandemic. We also sought to

understand how the COVID-19 pandemic sparked innovation. We therefore conducted a qualitative study asking about experiences of clinicians delivering care in ICU recovery clinics during the COVID-19 pandemic.

## Methods

### Participants, Sampling, and Recruitment

The study was conducted with international ICU recovery clinic interprofessional clinicians involved with the Critical and Acute Illness Recovery Organization (CAIRO) (19). CAIRO is a global collaborative of interdisciplinary groups dedicated to improving outcomes for ICU survivors and their families; its mission is to promote and support global collaboratives to advance innovations in critical and acute illness recovery (19, 20). Inclusion criteria were as follows: actively working in clinical practice in ICU recovery program, access to telephone and/or computer with Internet for audio interview, and English speaking (19). The study design and protocol were approved by the University of Pittsburgh Institutional Review Board (STUDY19090073).

A stratified sampling strategy was utilized to recruit ICU recovery program clinicians from diverse practice backgrounds (e.g., medicine, nursing, rehabilitation services, social work, psychology, and pharmacy) between February and March of 2021 (19). Diversity in age, sex, and years of experience were also considered during clinician sampling. Snowball sampling was utilized to allow participants to suggest colleagues from other disciplines at their respective sites who might provide valuable insights based on clinical experience and expertise (19, 21).

### Data Collection

A semistructured interview guide (see File E1 in the online supplement) with prompting

questions was generated through iterative discussion and a review of the literature (9, 12, 16, 22–25). After informed consent was secured, a female critical illness recovery nurse practitioner with qualitative methodology and interviewer experience (T.L.E.) conducted all study interviews by audio or video call. The interviewer was known to some participants through their engagement involvement in CAIRO (19). Interviews ranged between 15 and 35 minutes. The interview was audio recorded, transcribed verbatim, and completely de-identified.

### Data Analysis, Researcher Reflexivity, and Rigor

Thematic analysis integrating *a priori* assumptions grounded in current critical illness survivor literature was applied to both inductively and deductively analyze data across the interviews. Thematic saturation was defined as no new codes or themes observed across interviews. Five key steps were included in the data analysis process (File E2). Three trained coders with expertise in critical illness recovery care independently undertook preliminary sweeps of the data to familiarize themselves with the interview (19). The coding team then independently coded a subset of five transcripts line by line, resolving any differences by discussion, before jointly creating a preliminary codebook. By incorporating more than two coders on the coding team, a level of intersubjectivity within the team was achieved, thereby providing an additional level of scrutiny and rigor to the coding process (19, 26, 27). All transcripts were coded once, with intermittent double coding (20% of transcripts) to avoid idiosyncratic coding. Iterative refinement of the codebook occurred after every five transcripts (19). After coding was completed, the analysis team (T.L.E., L.M.B., and J.M.) reviewed all statements, discussed differences, and resolved remaining discrepancies by consensus (19).

**Author Contributions:** Conceived the study: T.L.E., S.A., and C.M.S. Designed the study: T.L.E., S.A., and C.M.S. Acquired the data: T.L.E. Performed qualitative data analysis: T.L.E., L.M.B., and J.M. Drafted the manuscript: T.L.E., L.B., and J.M. All authors critically revised the manuscript for important intellectual content, approved the final version to be published, and take responsibility for the integrity of the data and the accuracy of the data analysis.

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**Table 1.** Characteristics of participants

Variable	Participant Data (N = 29)
Age, median (IQR)	42 (39–52)
Sex, no. (%)	
Female	21 (72.4)
Male	8 (27.6)
Professional role, no. (%)	
Physician	10 (34.5)
Nurse	5 (17.2)
Pharmacist	4 (13.8)
Physical therapist	3 (10.3)
Social worker	2 (6.9)
Psychologist	2 (6.9)
Respiratory therapist	1 (3.4)
Speech therapist	1 (3.4)
Occupational therapist	1 (3.4)
Practice setting, no. (%)	
Academic	20 (69.0)
Nonacademic	4 (13.8)
Both	5 (17.2)
Years in professional role, median (IQR)	16 (7–21)
Years working in post-ICU clinic, median (IQR)	3 (1–4)

Definition of abbreviations: IQR = interquartile range; ICU = intensive care unit.

Coding was grouped under key themes in a working analytical framework and iteratively checked across the interview transcripts (19). Data analysis was performed using NVivo12 (version 12, QSR International) to code and query transcripts and create an audit trail. During the final analysis, the first author (T.L.E.), supported by discussions with the rest of the team, developed final themes. Key quotes to support the findings were then independently extracted (by T.L.E., L.M.B., and J.M.). This study was reported using the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (28) (File E4).

## Results

Twenty-nine participants from 15 sites in Canada, the United States, and the United Kingdom participated in the study. Participants included physicians, nurses, social workers, psychologists, rehabilitation specialists, and pharmacists (Table 1). Participating sites are listed in File E3. The sample largely comprised female participants (72.4%,  $n = 21$ ) working in an academic setting (69.0%,  $n = 20$ ). Providers served in their current role for a median of 16 years (interquartile range [IQR], 7–21) and worked in an ICU recovery clinic for a

median of 3 years (IQR, 1–4). Thematic saturation occurred after reviewing 29 transcripts.

Participants identified three patient-level key themes that influenced care delivery in ICU recovery programs during COVID-19: 1) social isolation, 2) decreased emotional reserve in patients and families, and 3) substantial social care needs (Figure 1). Changes reported in ICU recovery clinic care delivery in response to these newly recognized needs are presented (Table 2). Identified gaps in ICU recovery clinic care delivery during the COVID-19 pandemic included a need for multidisciplinary team members, access to care issues (e.g., digital poverty, health insurance coverage, language barriers), and altered family engagement (Figure 2).

### Theme 1: Social Isolation

The COVID-19 pandemic has led to social isolation of critical illness survivors during the acute phase of their illness as well as in the posthospital setting. Support from and engagement with families and loved ones was limited, as hospital visitation was restricted during the height of the pandemic.

*“... particular to the COVID ICU survivors is the family isolation... they’ve gone through, and I don’t mean gown and PPE [personal protective equipment]. We’re obviously talking about deprivation of contact with their family and with anybody, actually, during the illness... the hardest thing going through this whole horror was not being able to have a family member with them.”* (Participant #9; physician)

Additionally, survivors were confined to home postdischarge, further exacerbating the effects of social isolation on recovery.

### Patient-Specific Themes as Identified by Post-ICU Team Members



**Figure 1.** Key themes from patient characteristics contributing to the evolution of care delivery in the post-ICU (intensive care unit) clinic setting.

**Table 2.** Changes in care delivery in the post-ICU clinic setting

#### Clinician-level changes

Growing awareness of healthcare disparities and inequities  
Recognition of financial effects of illness  
Refinement of communication skills  
Focus on reconstructing the illness narrative

#### Program-level changes

Expansion of care delivery modes (e.g., telemedicine)  
Efforts to integrate social care

Definition of abbreviation: ICU = intensive care unit.

### Identified Gaps in ICU Recovery Care Delivery during the COVID-19 Pandemic



**Figure 2.** Interprofessional team member identified gaps in post-ICU (intensive care unit) clinic care delivery. COVID-19 = coronavirus disease.

“... they’re not able to see their family, or their friends and, so, that’s a burden in terms of their healing and the recovery.” (Participant #17; registered nurse)

**Clinician- and practice-level changes in care delivery.** Recognizing the difficulties that posthospital social isolation caused for in-person medical appointments, many ICU recovery programs instituted a telehealth program to decrease care fragmentation caused by pandemic policies and social isolation.

“So, very early on, we were not able to see patients in our post-ICU clinic, we were concerned about their safety, really, and leaving their home. And then, our nurse practitioner was able to start a telemedicine program . . . to follow up with them.” (Participant #7; physical therapist)

Providers described the increased importance of reconstructing the illness narrative for the survivor and their family members as a result of their isolation during the hospital stay.

“... most of the time when the patients are not aware of what’s happening . . . the family’s role is they put . . . these big black holes together for the patient . . . the family were there to tell them, but now they are not there anymore . . . It’s hard on the patient, and it’s hard on the family because they feel that they have . . . abandoned their loved ones.” (Participant #21; registered nurse)

**Gaps in ICU recovery care delivery.** Lack of family engagement within the ICU affected the ability of patients to attend ICU recovery follow-up services.

“There are some patients that we weren’t able to follow up with because I didn’t really get a chance to connect with the family, in person [in the ICU].” (Participant #2; pharmacist)

Many providers reported difficulties with the initiation and implementation of telehealth services.

“Some of the care has been delivered remotely. We’ve done some telephone conferencing. I think that is better than nothing, but there are aspects of the clinic that can’t be done over the phone. So, I think it’s not optimal, but we have adapted.” (Participant #10; pharmacist)

### Theme 2: Decreased Emotional Reserve in Patients and Families

A decrease of emotional reserve in survivors and their family members was described by providers as a result of growing anger and frustration along with the stigma of illness while attempting to recover during a pandemic.

“... they [clinic patients] demonstrate frustration. I think many of us have COVID-backed fatigue . . . and adding on top of that everything that they had gone through for their rehabilitation, or their stay in the ICU, it’s a lot for them

to handle. So, there’s a lot of frustration and anger towards the system, towards the situation.” (Participant #8; pharmacist)

**Clinician- and practice-level changes in care delivery.** In response to the declining emotional health of critical illness survivors, providers reported increased efforts on refining communication skills such as increased empathy and listening during ICU recovery clinic visits.

“I’ve listened more . . . I think I’ve been definitely more empathetic, listening to their issues and prioritizing their needs more . . . taking much more time and explaining why things are happening. So, I am asking more questions . . . not taking anything for granted.” (Participant #5; speech language therapist)

**Gaps in ICU recovery care delivery.** Some providers described the frustrations felt within their ICU recovery clinics to address these emotional health issues.

“... we had a six-month hiatus, and we were all getting more and more anxious . . . you can’t just dump these people [patients]. We’ve got to do something for them . . . [patients are having] all these emotions at home with no one to talk to about it because they didn’t know whether that [news reports about ICUs] was them or not. So, the people that were in ICU just before COVID struck were psychologically quite scarred.” (Participant #14; physician)

### Theme 3: Substantial Social Care Needs

The vast majority of providers described the extensive social care and financial needs of ICU recovery clinic patients.

[in reference to clinic patient] “. . . she had social needs, utility bills, getting groceries, problems with transportation. . . . But what I see . . . across the board for some of our patients who have Medicaid, they are not fully aware of all that is available for them.” (Participant #23; advanced practice nurse)

The cumulative effects of racism and inequality were perceived as disproportionately impacting COVID and non-COVID critical illness survivors across communities.

*“This has definitely disproportionately affected the Hispanic population. . . . what’s unique is that . . . we’re seeing . . . the member of the household that . . . the rest of the family has most likely had COVID as well . . . but this is the one that it affected the worst, obviously. . . . It’s almost, it’s impossible to, for them to be able to isolate in multigenerational homes.”* (Participant #2; pharmacist)

*“And what was eye opening was the healthcare disparities . . . a lot of minorities we saw post-COVID . . . and with COVID, a lot of African Americans.”* (Participant #22; physician)

Conversely, one provider described their experience within an area of financial privilege, further highlighting the differences in response and care for underserved populations.

*“Honestly, we have one of the lowest visible minority [populations] out of any city in [state]. People are generally upper middle class, and our local health unit has just done an absolutely amazing job, as well. . . . they actually repurposed all of the restaurant health care inspectors . . . into retirement nursing home care inspectors. So . . . all of our nursing homes had appropriate training and PPE [personal protective equipment] and all the staff that they needed.”* (Participant #15; physician)

**Clinician- and practice-level changes in care delivery.** Many providers discussed their increased attentiveness to the financial burdens resulting from critical illness within the context of the COVID-19 pandemic.

*“. . . folks are already struggling due to a pandemic and potentially other family members losing their jobs and then critical illness on top of that. They have medical bills, they have delayed return to work, so financial needs are one that I think I’ve been noticing more than I did previously.”* (Participant #1; physician)

Additionally, providers acknowledged differences in healthcare quality and delivery for COVID and non-COVID critical illness survivors.

*“We’ve seen a lot of people who’ve come to our clinic . . . want to transfer all of their care to us for the longer term . . . a*

*lot of them talk about, ‘This is the best health care I’ve ever had.’ These are mainly people of color. And I felt just the difference in care that they received.”* (Participant #20; social worker)

**Gaps in ICU recovery care delivery.** Despite many providers appreciating healthcare disparities, they reported operational barriers and structural gaps to mitigating inequity in the ICU recovery clinic.

*“. . . because of the way that it’s [COVID] affected underserved populations, we have a lot of patients that are not insured, not documented. And, so, it’s difficult to get all of the medication access that we can otherwise get. We have had a lot of great resources, but that has definitely been a challenge.”* (Participant #26; pharmacist)

*“So, we had to change it [post-ICU program] to a virtual platform and then you start talking about digital poverty. And [location of program] is a very deprived area.”* (Participant #14; physician)

Some providers shared gaps in addressing social care needs and efforts to integrate delivery of social care through the ICU recovery clinic.

*“. . . in the setting of COVID, I think there are some pretty extensive needs from a job loss perspective. Access to health care and insurance, support for caregivers, and provision of varying home needs. So, I wish that we had that aspect, but we don’t. We have a community health worker who’s been great but has limited capacity relative to if we had a dedicated social worker.”* (Participant #28; physician)

Concern was also voiced regarding language barriers and the lack of properly translated materials for non-English-speaking patients and families.

*“We’ve had . . . multiple languages . . . we realized we can’t give them the information we want because it’s not translated into the right language. . . . and is it so exhausting for them to really tell me how everything is because we’re speaking through a translator? I do worry about that a lot.”* (Participant #29; advanced practice nurse)

## Discussion

The authors of this multicenter qualitative study aimed to better understand the patient-level factors affecting ICU recovery clinic care and changing clinical thinking during the COVID-19 pandemic. Providers from 15 international sites described the evolution of delivery requirements and notable changes in patient demographics and healthcare needs for those seen in the ICU recovery clinic. The integration of social care and focus on matching resources to diverse patient groups were perceived as key to delivering sensitive and beneficial services.

Providers across the interviews described that those recovering from severe COVID-19 often presented to ICU recovery clinics with more complex issues than non-COVID-19 patients. Providers specifically highlighted the social and economic problems encountered by patients after severe COVID-19 and the corresponding intersection with recovery. The emergence of these issues drove ICU recovery clinic service evolution, resulting in more emphasis on addressing social care needs and integrating newly created social welfare pathways. However, many ICU recovery clinic teams struggled because of inadequate personnel capacity to address social issues. Previous research has highlighted that an integrated social and clinical care approach is feasible and acceptable in the ICU recovery clinic setting (29), and management of social issues (e.g., welfare support, employment advice, food security) should be a central component of ICU recovery services (30). Interventional research exploring the full impact of integrated social and clinic services for critical care survivors could greatly inform standardized evidence-based ICU recovery clinic service models.

It is well established that COVID-19 has disproportionately affected underresourced and ethnically diverse communities internationally (31, 32). These inequalities were also reflected in the ICU recovery setting, where access to care, alongside detailed recovery information—a key mechanism known to support patient and family recovery—was lacking (12). ICU recovery clinic providers attempted to adapt services in response to these “newly prominent issues” (e.g., using translators, introducing digital platforms). However,

they recognized that these solutions were far from adequate and may elicit further health disparities (33, 34). Research describing inequalities in health and access to health care, both in relation to deprivation and race, is not new (35–37). There is an urgent need to increase research capacity, focusing on delivering interventions, which are inclusive and reduce health inequalities, across different communities. This research must include appropriate and thoughtful patient and community engagement to ensure that any potential solutions are meaningful and sustainable.

Providers also described patient challenges with emotional reserve during recovery from critical illness. Because of COVID-19 visitation restrictions, family members were often not present in the hospital during the patient's COVID-19 acute illness. This resulted in a disconnect between the patient experience and family knowledge, resulting in a changing dynamic and social isolation. Hospitalization memory gaps, typically filled in by family members, could not be answered. This contributed to the patient's inability to reconstruct an illness narrative around their critical illness, exacerbating emotional upset and a lack of

understanding about the current situation. The use of patient diaries, ICU visits, and the use of care debriefings have been proposed as mechanisms to help fill this important memory gap and improve emotional reserve (12, 13, 38). More research in this area is needed to improve care outcomes.

This study is one of a few to explore ICU recovery clinic care delivery changes due to the COVID-19 pandemic. Its interprofessional, international approach has captured a wide array of clinician experiences, which has generated tangible clinical implications. However, this work does have limitations. We acknowledge a risk of selection bias, as no interprofessional outside of the CAIRO network participated, limiting generalizability to the entire ICU recovery clinic clinician population. To minimize cultural impact, we enrolled a mix of clinicians on the basis of length of post-ICU clinic collaborative membership, including newer members along with those having long-standing involvement. Additionally, some issues identified may be specific to the international context of the provider. Our analysis has utilized rigorous qualitative methods, including specific approaches to enhance reproducibility, such as a detailed analytical approach across an international

team, and member checking. Nonetheless, other interpretations may be possible.

## Conclusions

This study provides a deeper understanding of impact of the COVID-19 pandemic on critical illness recovery care, including marked differences in patient demographics and healthcare needs. Efforts to integrate social care, address financial needs, refine provider communication skills, and enhance focus on reconstructing the illness narrative became important priorities during the ICU recovery clinic visit. These changes among the expansion of care delivery modes allowed for a timely evolution of services to better address patient and caregiver recovery needs. ■

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