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PATIENT AND CAREGIVER-DERIVED HEALTH SERVICE IMPROVEMENTS FOR BETTER CRITICAL CARE RECOVERY

--Manuscript Draft--

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Abstract:	Objective: To engage critical care end-users (survivors and caregivers) to describe their emotions and experiences across their recovery trajectory, and elicit their ideas and solutions for health service improvements to improve the ICU recovery experience. Design: End-user engagement as part of a qualitative design using the Framework Analysis method. Setting and Patients: Data generation occurred via interviews with patients and caregivers identified through the Society of Critical Care Medicine's THRIVE international collaborative sites (follow-up clinics and peer support groups). Main Results: Eighty-six interviews were conducted. The following themes were identified: 1. Emotions and experiences of patients – Loss of former self; Experiences of disability and adaptation; 2. Emotions and experiences of caregivers – Emotional impacts, adopting new roles, and caregiver burden; Influence of gender roles; Adaptation, adjustment, recalibration; and 3. Patient and caregiver-generated solutions to improve recovery across the arc of care - Family-targeted education; Expectation management; Rehabilitation for patients and caregivers; Peer support groups; Reconnecting with ICU post discharge; Access to community based supports post discharge; Psychological support; Education of issues of ICU survivorship for health professionals; Support across recovery trajectory. Themes were mapped to a previously published recovery framework (Timing it Right) that captures patient and caregiver experiences, and their support needs across the phases of care from the event/diagnosis to adaptation post-discharge home. Conclusions: Patients and caregivers reported a range of emotions and experiences across the recovery trajectory from ICU to home. Through end-user engagement strategies many potential solutions were identified that could be implemented by health services and tested to support the delivery of higher-quality care for ICU survivors and their caregivers that extend from tertiary to primary care settings.
Response to Reviewers:	Response to Reviewers

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“However, we did not specifically investigate differences across diverse cultures within this study, nor did we collect demographic information such as race, ethnicity, ancestry, religion. Such information would be important to collect and incorporate into future research design as these factors may result in a different ICU survivorship experience, as well as access to healthcare, and interactions with health systems.”

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On behalf of the Society of Critical Care Medicine’s Thrive initiative

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ABSTRACT

Objective: To engage critical care end-users (survivors and caregivers) to describe their emotions and experiences across their recovery trajectory, and elicit their ideas and solutions for health service improvements to improve the ICU recovery experience.

Design: End-user engagement as part of a qualitative design using the Framework Analysis method.

Setting: The Society of Critical Care Medicine's THRIVE international collaborative sites (follow-up clinics and peer support groups).

Subjects: Patients and caregivers following critical illness and identified through the collaboratives.

Interventions: Nil.

Measurements and Main Results: Eighty-six interviews were conducted. The following themes were identified: 1. Emotions and experiences of patients **–** *Loss of former self; Experiences of disability and adaptation;* 2. Emotions and experiences of caregivers – *Emotional impacts, adopting new roles, and caregiver burden; Influence of gender roles; Adaptation, adjustment, recalibration;* and 3. Patient and caregiver-generated solutions to improve recovery across the arc of care - *Family-targeted education; Expectation management; Rehabilitation for patients and caregivers; Peer support groups; Reconnecting with ICU post discharge; Access to community based supports post discharge; Psychological support; Education of issues of ICU survivorship for health professionals; Support across recovery trajectory.* Themes were mapped to a previously published recovery framework (Timing it Right) that captures patient and caregiver experiences, and their support needs across the phases of care from the event/diagnosis to adaptation post-discharge home.

Conclusions: Patients and caregivers reported a range of emotions and experiences across the recovery trajectory from ICU to home. Through end-user engagement strategies many potential solutions were identified that could be implemented by health services and tested to support the

delivery of higher-quality care for ICU survivors and their caregivers that extend from tertiary to primary care settings.

INTRODUCTION

Recovery following critical illness presents many challenges to patients and caregivers as they navigate the health system. These include post-intensive care syndrome (1); loss of former roles and societal participation, and negative effects on finances and employment (2-5). Survivors' informational and emotional support needs differ across the recovery trajectory (6); as described in the Timing it Right Framework (7). However, few studies directly link survivor and caregiver experiences to health service improvements, and optimal timing of intervention delivery across the recovery arc.

Engaging patients and caregivers in health system improvements utilises their rich and meaningful experiences and improves both individual-level outcomes and health service delivery (8-10). However, there are few published examples of patient and family engagement in critical care (8). Redesign of post-ICU models of care is required to increase survivor self-care engagement, monitor for signs of deterioration, intervene early, and reduce costs (11). The aim of this study was to engage with ICU survivors and caregivers to: 1. Describe their emotions and experiences across their recovery trajectory from ICU to home; 2. Elicit their ideas and solutions for health system improvements for enhanced ICU recovery across the recovery arc.

MATERIALS AND METHODS

This study is reported using the Consolidated Reporting of Qualitative Research (COREQ) checklist (12).

Setting and ethical approval

This multi-site, international study was conducted across the Society of Critical Care Medicine's Thrive Peer Support Collaborative and/or Clinic Collaborative hospital sites in the United States (US), United Kingdom (UK), and Australia (13). Institutional ethical approval was gained from Western Health Low Risk Human Research Ethics Panel, Australia (HREC/17/WH/170); Vanderbilt University Institutional

Review Board, US (171299); and the South West (Cornwall and Plymouth) Research Ethics Committee, UK (18/SW/0137).

Study design

A qualitative study design using Framework Analysis was used. A feedback-eliciting model of engagement, incorporating interactive communication and consultant between clinicians and participants, was used to generate ideas and solutions (8).

Participants, sampling and recruitment

This dataset was part of a larger international qualitative research program that sought to understand the global impact of ICU recovery programs on patients (14-15), caregivers (16), and the clinicians delivering these program (13, 17). Participants were recruited through invitation at post-ICU programs. Potential participants were identified and invited to participate in the study by the lead clinicians running the program, if attending a post-ICU program at the respective sites (Supplementary Table 1).

Participants were screened against the following: i) inclusion criteria - English-speaking patients older than 18 years admitted to the ICU; ii) exclusion criteria - ongoing severe neurological and/or cognitive impairment, or continued inpatient status in a hospital or rehabilitation setting at the time of the study. Criterion purposive sampling was used that seeks out and selects cases that meet predetermined criterion of importance. We aimed to select cases to promote socio-demographic and geographic diversity in the sample by seeking participants from various international hospital sites, educational levels, and employment statuses. We also sought to understand different recovery trajectories across time and recruited patients at different time-points in the post-hospital phase.

If willing to participate, an interview was arranged with the respective study coordinator in each country, who was not involved in the patient’s care, and verbal consent sought at the time of interview. ~~Purposive sampling was used to obtain a cross-section of sociodemographic diversity by recruiting participants from different hospital sites, educational levels, employment statuses, and time points post-hospital stay. We included English-speaking adults admitted to ICU; and excluded those with severe neurological, or cognitive impairment. If willing to participate, consent was obtained and an interview was conducted by the study coordinator in each country (not involved in participants' care).~~

Data collection and generation

A semi-structured interview guide was developed using pre-existing literature (Supplementary Appendix 1). The questions were reviewed by independent survivors and caregivers from each country to ensure local context and interpretation, as well as an independent expert qualitative researcher. Interviews were conducted by four researchers (J.M. – ICU nurse researcher, L.M.B. – ICU nurse researcher, E.H. ICU physiotherapist researcher, J.J. ICU psychologist researcher) with extensive experience in qualitative interviewing and who were not involved in the participant's care. The interviewers explained their professional background and project role to the participants. Interviews were conducted via telephone and lasted between 20-60 minutes. Only the interviewer and participant were present for the interviews. Interview recordings were transcribed and data were analysed using Dedoose software.

Data analysis and rigor

Framework Analysis was used to identify major themes across seven stages (18) (Supplemental Appendix 2 Methods). Each transcript was coded with meaningful passages and cross-checked between two researchers. Two separate working analytical frameworks were developed for emotions and experiences of patients and caregivers (Supplementary Table 2~~1~~) and their suggested solutions (Supplementary Table 3~~2~~), including comparison and contrasting of themes between patient and caregiver data at a group level (not at an individual dyad level). To ensure rigor, regular crosschecking of analyses and data was undertaken by the research team (KH, EH, TH, NL). Data saturation was reached as assessed by the primary analysis team and the lead researchers – where no new information was elicited from the data. Member checking occurred prior to and post data analysis.

To link patient and caregiver experiences with their suggested solutions for health systems improvements, we mapped the results to the Timing It Right framework (Figure 1). This framework encompasses patient and caregiver experiences, and their support needs across the phases of care: (1) event/diagnosis; (2) stabilization; (3) preparation; (4) implementation; (5) adaptation (6, 7, 19).

RESULTS

Eighty-six interviews were completed with 66 patients, and 20 caregivers (Table 1). The majority of participants were middle-aged, female, admitted to ICU for sepsis (patient only), recruited from the US, had participated in some form of ICU recovery program, and were advanced in their recovery trajectory (two years post-discharge). Due to the use of purposive criterion sampling, of those participants identified by site leads and invited to participate, none were excluded.

The major themes were categorised as follows (Figure 1):

1) Emotions and experiences of patients - patients described their emotional challenges and experiences across the recovery trajectory (Supplementary Table 4~~3~~).

2) Emotions and experiences of caregivers – as above, for caregivers; these overlapped in some areas with patients, but were also distinctly different (Supplementary Table 4~~3~~).

3) Patient and caregiver-derived solutions – using their experiences, new ideas and solutions for health service improvements were proposed (Figure 2, Supplementary Table 5~~4~~).

~~Timing it Right Framework - Phase 1 Event~~

1) Emotions and experience of patients

Loss of former self

I~~– I~~n the ICU, patients described grief, loss, and lack of control due to the environment and illness. The ICU admission was described as a significant health shock: "*I lost a lot when I went into that hospital. Three weeks later coming out… I'm not the same person*" (~~Participant~~ Patient 23). Patients grieved the loss of the person they were prior to the ICU, and had less confidence as a result of their reduced abilities: *"I am nowhere near the person I used to be."* (Patient 23). Some grieved a loss of identity related to their physical appearance that was inherently important to how they and others perceived them: *"As a trans woman it's very hard to affirm your gender a lot… being a lot skinnier, not having as much of my curves was really, really hard for me. These were things I had associated with my femininity..."* (Patient 26). Following hospital discharge, patients described a loss of their former social networks, impact on their life goals, and loss of their independence: *"The family that I used to work with is gone…Whether you go to college with a group and you become buddies or whatever, but once you've gone, you're gone. So, you very seldom hear from your work friends anymore*" (Patient 8).

Experiences of disability and adaptation

~~–.~~ As recovery began, patients were overwhelmed with the magnitude of disability: *"God, it was so much… learning how to use the restroom again, learning how to walk again, learning how to talk …"* (~~Participant~~Patient 9), and their adaptation to their new disabilities which impacted their cognitive, mental, and physical health: "*It's an up and down roller coaster beyond belief*" (~~Participant~~Patient 6). On leaving hospital, patients described being fearful about the transition out of a highly supportive environment where help was constantly available: *"I was on my own after I'd been attended to and watched over…incessantly."* (Patient 7).

Following hospital discharge, patients needed to adapt to newfound disabilities that impacted their physical, mental, emotional, and cognitive health as one participant described: *"I have severe cognitive problems. I used to read voraciously, I can barely read anymore."* (Patient 20). In the longer-term, some patients described an ongoing psychological burden associated with continued interactions with the health system, where they felt re-traumatised. This hindered their ability to recover psychologically: *“Every time I ended up going to the ER… questions came about of have you ever been trached? Having to relive the situation for so many years from the complications…, could be the most agonizing thing to move on from.”* (Patient 9).

2) Emotions and experiences of caregivers

Emotional impacts, adopting new role, and caregiver burden

~~– ~~W~~w~~ith the initial health shock of the ICU admission, caregivers also grieved the loss of the person: *“he went as one person and came out as another one.”* (~~Participant ~~Caregiver 21). On leaving hospital, caregivers were also fearful about what it meant for them to adopt the role of caregiver with lesser supports available: *“it was really tremendously overwhelming, the feeling of just being lost and scared and so unsure of what you’ve got to do or what's ahead of you…”* (Caregiver 1). As patients began to recover, caregivers reflected on adopting new roles such as decision-making and advocacy: *“I had to kind of advocate for him. Yeah, all those times there had been something seriously wrong with him… so I'm glad I did”* (Caregiver 27). Simultaneously, they had to maintain their usual activities and roles and these competing demands and roles culminated in caregiver burden.

~~**Adopting new roles, and caregiver burden** – As patients began to recover, caregivers reflected on adopting new roles such as decision-making and advocacy: *“I had to kind of advocate for him. Yeah, all those times there had been something seriously wrong with him… so I'm glad I did”* (Participant 27). Simultaneously, they had to maintain their usual activities and roles and these competing demands and roles culminated in caregiver burden.~~

Adaptation, adjustment, recalibration

Caregivers had to adapt to new responsibilities for managing the patient’s health issues post-discharge. At times these responsibilities led to caregivers feeling stretched as they had to manage competing demands: “*I had to take on all the responsibilities… I had to walk the dogs every single day, as he had no strength*” (Caregiver 48). Over time caregivers appeared to adjust to their role as caregiver: *“…As the months went on, I felt a lot more comfortable as a caregiver”* (Caregiver 27). Caregivers then recalibrated their role as the patient recovered: *“Him being able to really kind of take care of himself… kind of gave me back myself*” (Caregiver 79).

Influence of gender roles on caregiving

Caregivers described having to manage typical gender roles and expectations regarding household tasks done prior to critical illness, which was stressful for them at times: *“I'm sure the kids get upset because ‘Mommy used to always do this, and Daddy, you don't know how to make my lunch. You put the peanut butter on the wrong side of the bread’…”* (Caregiver 4). Caregiving roles and expectations needed to be renegotiated: *“he* [patient] *had decided… I was gonna be the changer of his colostomy for the rest of his life which was ridiculous. So finally, I just planned a trip, and I said ‘You're gonna have to figure this out, I'm leaving’…”* (Caregiver 79).

3) Patient and Caregiver Generated Solutions

Family-targeted e~~E~~ducation, expectation management, and involvement of caregivers - ~~–~~Both survivors and caregivers suggested family-targeted education to better understand changes occurring to the patient especially in ICU and specifically related to delirium and cognition: *“Be blunt, tell them exactly what's going to happen”* (~~Participant~~ Caregiver 17). S~~**Expectation management –** S~~urvivors described the importance of focusing on expectation management, avoiding giving false hope, and normalising the dynamic nature of recovery: *“what's normal, what's abnormal?”* (~~Participant~~Patient 52). Caregivers suggested health professionals should help them to maintain hope and motivation as the patient recovers, and help them understand expectations for recovery. Participants suggested increasing family involvement in rehabilitation, including supportive communication to engage families throughout. Carer training that involved supervising carers looking after the patient prior to hospital discharge, was also suggested.

Reconnecting with ICU post-discharge and educating health professionals – Survivors and caregivers suggested methods to reconnect to the ICU. These included use of a journal for their ICU stay to assist recovery, being able to make a direct phone call follow up to the ICU following discharge, and access to a return visit to the ICU if desired: *“There should be some option to go back, or to remain connected with people there, or even just a place to ... even if you don't need any clinical help beyond that, just to plan to come back and be able to reconnect with your experience.”* (Patient 7). Caregivers suggested improving medical education on post-intensive care syndrome for health professionals, as one described: *“Part of the problem is that the doctors aren't being educated”* (Caregiver 21).

Access to community-based supports post discharge and support groups – Survivors suggested better assessment and access to post-discharge rehabilitation supports: *“I wonder how much faster I could have recovered had there been an assessment when I was discharged”* (Pai 18). Both survivors and caregivers cited many benefits of peer support groups including: *“Being able to discuss back and forth with people of like mind… people that can help you see things, and you know you're not by yourself”* (Participant 1). Participants described peer support as providing an opportunity to help others out of a sense of altruism. Suggestions were made to improve access and timing of support groups, e.g. early availability of support groups in the recovery trajectory.

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~~Timing it Right Framework: Phase 2 Stabilisation~~

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~~1) Emotions and experience of patients~~

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~~Experiences of disability and adaptation – . As recovery began, patients were overwhelmed with the magnitude of disability: “God, it was so much… learning how to use the restroom again, learning how to walk again, learning how to talk …” (Participant 9), and their adaptation to their new disabilities which impacted their cognitive, mental, and physical health: “It’s an up and down roller coaster beyond belief” (Participant 6).~~

~~**2)** Emotions and experiences of caregivers~~

~~Adopting new roles, and caregiver burden – As patients began to recover, caregivers reflected on adopting new roles such as decision-making and advocacy: “I had to kind of advocate for him. Yeah, all those times there had been something seriously wrong with him… so I'm glad I did” (Participant 27). Simultaneously, they had to maintain their usual activities and roles and these competing demands and roles culminated in caregiver burden.~~

~~**3)** Patient and Caregiver-generated Solutions~~

~~Expectation management – Survivors described the importance of focusing on expectation management, avoiding giving false hope, and normalising the dynamic nature of recovery: “what's normal, what's abnormal?” (Participant 52). Caregivers suggested health professionals should help them to maintain hope and motivation as the patient recovers, and help them understand expectations for recovery.~~

~~Timing it Right Framework: Phase 3 Preparation~~

~~**1)** Emotions and experience of patients~~

~~Experiences of disability and adaptation - On leaving hospital, patients described being fearful about the transition out of a highly supportive environment where help was constantly available: “I was on my own after I'd been attended to and watched over…incessantly." (Participant 7).~~

~~**2)** Emotions and experiences of caregivers~~

~~Emotional impacts and adopting new role – On leaving hospital, caregivers were also fearful about what it meant for them to adopt the role of caregiver with lesser supports available: “it was really~~

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~~tremendously overwhelming, the feeling of just being lost and scared and so unsure of what you've got to do or what's ahead of you..." (Participant 1).~~

~~3) Patient and Caregiver-generated Solutions~~

~~Rehabilitation for patients and caregivers – participants suggested increasing family involvement in rehabilitation, including supportive communication to engage families throughout. Carer training that involved supervising carers looking after the patient prior to hospital discharge, was also suggested.~~

~~Timing it Right Framework: Phase 4 Implementation~~

~~1) Emotions and experience of patients~~

~~Loss of former self – Patients grieved the loss of the person they were prior to the ICU, and had less confidence as a result of their reduced abilities: "I am nowhere near the person I used to be." (Participant 23). Some grieved a loss of identity related to their physical appearance that was inherently important to how they and others perceived them: "As a trans woman it's very hard to affirm your gender a lot... being a lot skinnier, not having as much of my curves was really, really hard for me. These were things I had associated with my femininity..." (Participant 26).~~

~~Experiences of disability and adaptation~~

~~Following discharge, patients needed to adapt to newfound disabilities that impacted their physical, mental, emotional, and cognitive health as one participant described: "I have severe cognitive problems. I used to read voraciously, I can barely read anymore." (Participant 20).~~

~~2) Emotions and experiences of caregivers~~

~~Adaptation, adjustment, recalibration – caregivers had to adapt to new responsibilities for managing the patient's health issues post discharge. At times these responsibilities led to caregivers feeling stretched as they had to manage competing demands: "I had to take on all the responsibilities... I had to walk the dogs every single day, as he had no strength" (Participant 48).~~

~~3) Patient and Caregiver Generated Solutions~~

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~~Reconnecting with ICU post-discharge – Survivors and caregivers suggested methods to reconnect to the ICU. These included use of a journal for their ICU stay to assist recovery, being able to make a direct phone call follow up to the ICU following discharge, and access to a return visit to the ICU if desired: "There should be some option to go back, or to remain connected with people there, or even just a place to ... even if you don't need any clinical help beyond that, just to plan to come back and be able to reconnect with your experience." (Participant 7)~~

~~Access to community-based supports post discharge – Survivors suggested better assessment and access to post-discharge rehabilitation supports: "I wonder how much faster I could have recovered had there been an assessment when I was discharged" (Participant 18).~~

~~Timing it Right Framework: Phase 5 Adaptation~~

~~1) Emotions and experience of patients~~

~~Loss of former self – Following hospital discharge, patients described a loss of their former social networks, impact on their life goals, and loss of their independence: "The family that I used to work with is gone...Whether you go to college with a group and you become buddies or whatever, but once you've gone, you're gone. So, you very seldom hear from your work friends anymore" (Participant 8).~~

~~Experiences of disability and adaptation~~

~~In the longer-term, some patients described an ongoing psychological burden associated with continued interactions with the health system, where they felt re-traumatised. This hindered their ability to recover psychologically: "Every time I ended up going to the ER... questions came about of have you ever been trached? Having to relive the situation for so many years from the complications..., could be the most agonizing thing to move on from." (Participant 9).~~

~~2) Emotions and experiences of caregivers~~

~~Influence of gender roles on caregiving – caregivers described having to manage typical gender roles and expectations regarding household tasks done prior to critical illness, which was stressful for them~~

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~~at times: "I'm sure the kids get upset because 'Mommy used to always do this, and Daddy, you don't know how to make my lunch. You put the peanut butter on the wrong side of the bread'…" (Participant 4). Caregiving roles and expectations needed to be renegotiated: "he [patient] had decided… I was gonna be the changer of his colostomy for the rest of his life which was ridiculous. So finally, I just planned a trip, and I said 'You're gonna have to figure this out, I'm leaving'…" (Participant 79).~~

~~Adaptation, adjustment, recalibration – Over time caregivers appeared to adjust to their role as caregiver: "…As the months went on, I felt a lot more comfortable as a caregiver" (Participant 27). Caregivers then recalibrated their role as the patient recovered: "Him being able to really kind of take care of himself… kind of gave me back myself" (Participant 79).~~

~~3) Patient and Caregiver Generated Solutions~~

~~Support Groups – Both survivors and caregivers cited many benefits of peer support groups including: "Being able to discuss back and forth with people of like mind… people that can help you see things, and you know you're not by yourself" (Participant 1). Participants described peer support as providing an opportunity to help others out of a sense of altruism. Suggestions were made to improve access and timing of support groups, e.g. early availability of support groups in the recovery trajectory.~~

~~Solutions spanning Timing it Right Framework: Phases 1-5 Event to Adaptation~~

~~Some patient and caregiver solutions spanned the entire arc of recovery, and were not applicable to distinct phases of the Timing it Right framework.~~

~~Psychological support~~Greater health system support across the care trajectory – Survivors described the importance of receiving information and being taught coping strategies to coun~~t~~eract the health impacts: *"It's such a big, significant event in your life… I probably needed some counselling to talk it out".* (Participant 16). Caregivers highlighted the importance of access to early and sustained psychological support. Participants suggested avoiding the term "new normal", implying this was a static view of the dynamic recovery trajectory. ~~S~~survivors and caregivers described a crucial need for

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improved support from the health system and health professionals during recovery. This included better access to psychological support, and better access to physical rehabilitation. Participants suggested the need for a staged reduction in assistance at each point of the transitions of care – for example, a step-down setting between the ICU and acute ward: *"like a mini ICU"* (Participant 2).

~~**Education of issues of ICU survivorship for health professionals** – Caregivers suggested improving medical education on post-intensive care syndrome for health professionals, as one described: *"Part of the problem is that the doctors aren't being educated"* (Participant 21).~~

~~**Support across recovery trajectory** – survivors and caregivers described a crucial need for improved support from the health system and health professionals during recovery. This included better access to psychological support, and better access to physical rehabilitation. Participants suggested the need for a staged reduction in assistance at each point of the transitions of care – for example, a step-down setting between the ICU and acute ward: *"like a mini ICU"* (Participant 2).~~

DISCUSSION

In this large, international, multi-centre, qualitative study of critical care survivors and caregivers, the health impacts of critical illness required adaptation and adjustment over time, as participants moved through recovery stages captured in the TIR framework. Survivors and caregivers provided a range of solutions for health service improvements to aid recovery - family education, rehabilitation for patients *and* caregivers, peer support groups, support across transitions of care, access to community-based supports, reconnecting with ICU post-discharge, expectation management, health professional education, and psychological support.

This study highlights new themes in ICU recovery, with a diversity of perspectives not well-described in the literature previously. These include the influence of gender on the caregiving role; along with perspectives from transgender people, as well as data on how re-engaging with hospitals may be retraumatising for ICU patients, which could contribute to attrition in critical illness research. Some themes were well-described (loss of identity of patients and caregivers, new disability and associated grief), but perhaps the lenses used to date in interpreting perspectives of ICU recovery have been predominantly white males (which most participants in most studies are). Diversity in research inclusion is critical in contributing data that helps us to serve our communities, and this paper is one of the first to represent such diversity in viewpoints.

The solutions proposed have face validity that we believe address current gaps in care. The majority are low burden to implement within standard care as health services continue to manage the ongoing impacts of the COVID pandemic. Our data highlight that relatively simple strategies could impact quality of care - communication provided in different formats (verbal, written, visual, digital) such as a family information brochure (20), health professional education, engaging patients and their families in rehabilitation, and early and repeated setting of expectations to prepare for onward recovery. With increasing cost and complexity, alternative suggestions included early and sustained access to psychological services, or ICU step-down services. Most low-cost solutions could be readily implemented at key points in the transitions of care, although it should be acknowledged that while the evidence-base for these interventions are sparse, they might be useful foci for further research. However, identifying interventions that improve post-ICU outcomes in randomised controlled trials (RCTs) has proven elusive despite decades of research (21). Further, such interventions are often designed from the perspective of the health professionals only (10) and are often complex interventions (22). Given the costs and limitations of RCTs (23), and known delays to research translation, our findings suggest that making small, co-designed incremental improvements to the quality of care is a potentially more effective and impactful strategy to improve post-ICU outcomes (24, 25). A competing tension however, is that adopting disparate, fragmented approaches could further contribute to health inequities. Our data provides further support for partnering with patients and families to improve health care delivery – for example, the use of participatory research methods such as experience-based co-design may help insure the design of future interventions are inclusive and meet the needs of often under-served populations (10, 26).

These data highlight the importance of raising awareness of PICS beyond the ICU. While its early conceptualisation (1) may have raised awareness in the ICU, this knowledge is not well-translated to clinicians across the arc of recovery. Future studies could evaluate methods to better integrate care between ICU and primary care, for example to assist in screening for PICS post-ICU discharge (27), as well as providing educational material for patients and caregivers (i.e. an ICU passport). This is important in the context of strained health system resources, and limited availability of ICU follow-up services globally, where most post-hospital discharge support is accessed via primary care (28). Further, other opportunities might exist to leverage electronic medical records to use automated prompts for streamlined, efficient, and safe care during transitions.

This study included patients and caregivers, allowing data comparison. Another strength was use of the published TIR recovery framework, to help consolidate knowledge and advance the field of ICU recovery. Limitations include a motivated, engaged, and possibly privileged sample despite diversity; the majority of patients had attended a recovery program and had the physical and socio-economic capital to do so, impacting their experiences and proposed solutions. This study lacked representation of participants from low and middle-income countries, and non-English speaking backgrounds, whose recovery experiences and solutions may differ. Despite this, there was some common experiences of ICU survivorship irrespective of setting (high income countries, English-speaking cohort), which highlighted universal problems and potential solutions that could be adapted to individual healthcare settings. However, we did not specifically investigate differences across diverse cultures within this study, nor did we collect demographic information such as race, ethnicity, ancestry, religion. Such information would be important to collect and incorporate into future research design as these factors may result in a different ICU survivorship experience, as well as access to healthcare, and interactions with health systems. Future research should capture the experiences of more vulnerable cohorts (e.g. poor health literacy, socioeconomic disadvantage, rural etc.).

CONCLUSIONS

Survivors and caregivers reported a range of emotions and experiences across their recovery trajectories from the ICU to home. Using an end-user engagement approach, many potential and pragmatic solutions were identified. These solutions could be readily implemented and iteratively tested by health services to support the delivery of higher-quality recovery care for ICU survivors and their caregivers.

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FIGURE LEGENDS

Figure 1 Themes and Solutions – Timing It Right Framework

Figure 2 Patient and Caregiver-Derived Solutions

Figure 1

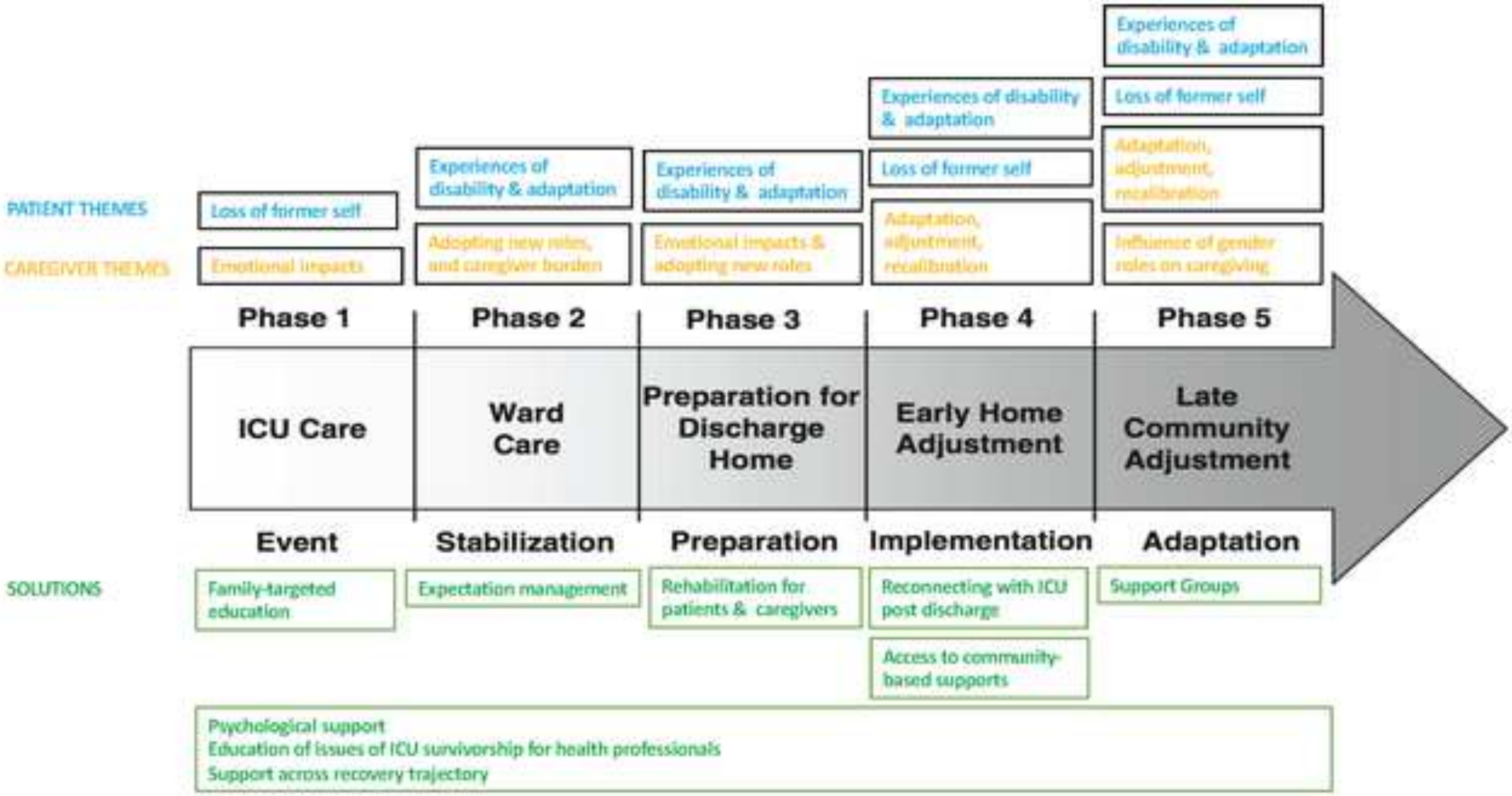
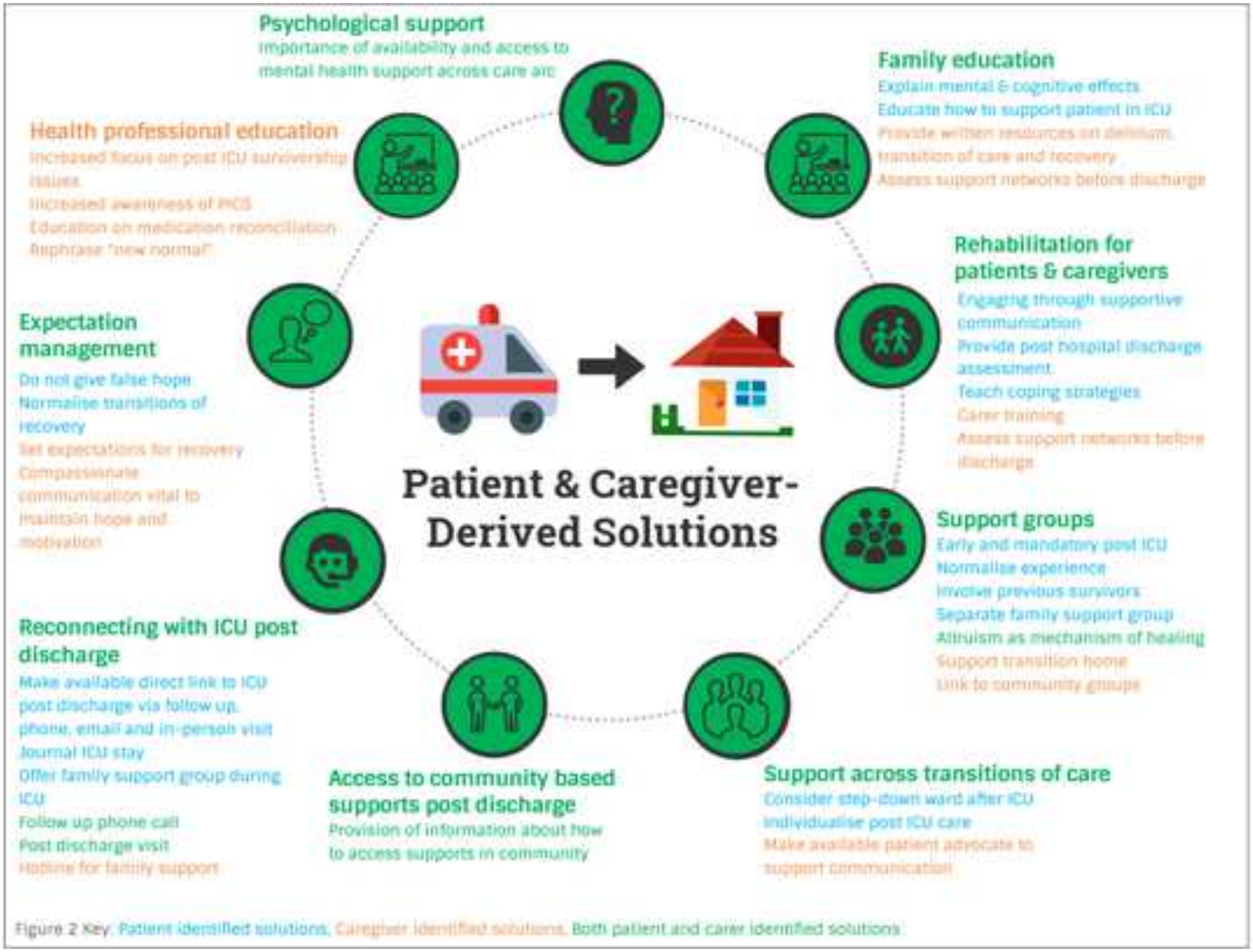

PATIENT THEMES
CAREGIVER THEMES
Loss of former self
Emotional impacts
Experiences of disability & adaptation
Adopting new roles, and caregiver burden
Experiences of disability & adaptation
Emotional impacts & adopting new roles
Experiences of disability & adaptation
Loss of former self
Adaptation, adjustment, recalibration
Experiences of disability & adaptation
Loss of former self
Adaptation, adjustment, recalibration
Influence of gender roles on caregiving
Phase 1
Phase 2
Phase 3
Phase 4
Phase 5
ICU Care
Ward Care
Preparation for Discharge Home
Early Home Adjustment
Late Community Adjustment
Event
Stabilization
Preparation
Implementation
Adaptation
SOLUTIONS
Family-targeted education
Expectation management
Rehabilitation for patients & caregivers
Reconnecting with ICU post discharge
Access to community-based supports
Support Groups
Psychological support
Education of issues of ICU survivorship for health professionals
Support across recovery trajectory

Figure 2



Patient & Caregiver-Derived Solutions

Psychological support

Importance of availability and access to mental health support across care arc

Family education

- Explain mental & cognitive effects
- Educate how to support patient in ICU
- Provide written resources on delirium, transition of care and recovery
- Assess support networks before discharge

Rehabilitation for patients & caregivers

- Engaging through supportive communication
- Provide post hospital discharge assessment
- Teach coping strategies
- Carer training
- Assess support networks before discharge

Support groups

- Early and mandatory post ICU
- Normalise experience
- Involve previous survivors
- Separate family support group
- Altruism as mechanism of healing
- Support transition home
- Link to community groups

Support across transitions of care

- Consider step-down ward after ICU
- Individualise post ICU care
- Make available patient advocate to support communication

Access to community based supports post discharge

Provision of information about how to access supports in community

Reconnecting with ICU post discharge

- Make available direct link to ICU post discharge via follow up, phone, email and in-person visit
- Journal ICU stay
- Offer family support group during ICU
- Follow up phone call
- Post discharge visit
- Hotline for family support

Expectation management

- Do not give false hope
- Normalise transitions of recovery
- Set expectations for recovery
- Compassionate communication vital to maintain hope and motivation

Health professional education

- Increased focus on post ICU survivorship issues
- Increased awareness of PICS
- Education on medication reconciliation
- Rephrase "new normal"

Figure 2 Key: Patient identified solutions, Caregiver identified solutions, Both patient and carer identified solutions

Table 1 Demographics

Table 1 – Participant demographics

	Patients (n = 66)	**Caregivers (n = 20)**
Age (years) Median (IQR)	52 (40, 62.5)	52 (46, 67)
Gender*, n (%)		
Female	40 (60.6)	17 (85)
Male	26 (39.4)	3 (15)
Self-described	-	-
Patient ICU admission diagnosis, n (%)		
Sepsis	28 (42.4)	-
Respiratory failure	15 (22.8)	-
Post-gastrointestinal surgery	5 (7.6)	-
Trauma	2 (3)	-
Other	16 (24.2)	-
Ventilated, n (%)		
Yes	57 (86.4)	-
No	9 (13.6)	-
Length of time since ICU discharge, n (%)		
<6 months	15 (22.8)	-
7-11 months	9 (13.6)	-
1-2 years	12 (18.2)	-
2-5-years	22 (33.3)	-
>5 years	8 (12.1)	-
Relationship to patient, n (%)		
Spouse/significant other	-	10 (50)
Parent	-	5 (25)
Sibling	-	3 (15)
Child	-	2 (10)

Nationality, n (%)		
United States	50 (75.7)	16 (80)
United Kingdom	13 (19.7)	2 (10)
Australia	3 (4.6)	2 (10)
Participated in an ICU recovery program, n (%)		
Yes	52 (79)	11 (55)
No	14 (21)	9 (45)

*Participants had the option of reporting gender as ‘Self-identified: (Specify if you wish)’ – however we did not receive any responses for this category.

Note: table adapted from *Transitions of care after critical illness – Challenges to recovery and adaptive problem solving Haines et al., CCM 2021*