# **ORIGINAL**

# Key mechanisms by which post-ICU activities can improve in-ICU care: results of the international THRIVE collaboratives

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#### **Abstract**

**Objective:** To identify the key mechanisms that clinicians perceive improve care in the intensive care unit (ICU), as a result of their involvement in post-ICU programs.

**Methods:** Qualitative inquiry via focus groups and interviews with members of the Society of Critical Care Medicine's THRIVE collaborative sites (follow-up clinics and peer support). Framework analysis was used to synthesize and interpret the data.

**Results:** Five key mechanisms were identified as drivers of improvement back into the ICU: (1) identifying otherwise unseen targets for ICU quality improvement or education programs—new ideas for quality improvement were generated and greater attention paid to detail in clinical care. (2) Creating a new role for survivors in the ICU—former patients and family members adopted an advocacy or peer volunteer role. (3) Inviting critical care providers to the post-ICU program to educate, sensitize, and motivate them—clinician peers and trainees were invited to attend as a helpful learning strategy to gain insights into post-ICU care requirements. (4) Changing clinician's own understanding of patient experience—there appeared to be a direct individual benefit from working in post-ICU programs. (5) Improving morale and meaningfulness of ICU work—this was achieved by closing the feedback loop to ICU clinicians regarding patient and family outcomes.

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**Conclusions:** The follow-up of patients and families in post-ICU care settings is perceived to improve care within the ICU via five key mechanisms. Further research is required in this novel area.

**Keywords:** Post-intensive care syndrome, Intensive care unit follow-up clinics, Peer support

#### Introduction

Recognition of adverse post-intensive care unit (ICU) outcomes has prompted clinicians to extend their practice beyond the physical location of the ICU [1–4]. In some settings, this post-ICU care takes the form of ICU follow-up clinics [1, 3, 5] or peer support programs [2, 6]. Such post-ICU programs have been coordinated by the Society of Critical Care Medicine's (SCCM) THRIVE initiative [7].

Most reports of post-ICU programs focus on the mechanisms by which such programs benefit patients and families dealing with ICU survivorship. However, an expert panel suggested that ICU care itself might change if clinicians knew more about outcomes beyond ICU discharge [8].

Yet no multi-center studies have identified generalizable mechanisms by which post-ICU programs could deliberately and systematically drive improvements in the quality of care delivered in the ICU. The aim of this study was to identify such mechanisms. It began using as a data source the perspectives of clinicians delivering post-ICU programs. We took advantage of the unique opportunity presented by the SCCM THRIVE Initiative to systematically probe for such feedback mechanisms among post-ICU programs in diverse health systems on three continents.

## **Methods**

# Setting and ethical approval

The institutional ethics committee of the principal investigator (KH) approved the study (HREC/17/WH/170) and consent was implied through participation.

# Study design

Qualitative inquiry was used to understand complex phenomena of post-ICU care [9, 10]. We chose qualitative inquiry rather than structured site surveys because there was scant prior literature on which to formulate close-ended questions, and we wished to hear participants describe their experiences in sufficient detail, that we could identify common underlying mechanisms.

# Participants, sampling and recruitment

Participants were recruited from the in-person meetings of the THRIVE collaborative sites for follow-up clinics

# Take-home message

ICU recovery programmes may offer benefits across the entire critical illness journey, for both clinicians and patients.

and peer support, at the 2018 SCCM Annual Congress. Congress was chosen as a point for data collection as it presented a unique opportunity to bring the international multidisciplinary research team together in-person. Purposive sampling strategies were employed to understand a range of experience within a variety of post-ICU programs.

The THRIVE collaboratives were established by the SCCM in 2017 (Post-ICU Clinic) and 2015 (Peer Support), to bring together critical care clinicians working to improve patients' and family members' outcomes. It was advertised internationally and has recruited new sites over the last 4 years, with four recruitment waves for the Peer Support Collaborative and two for the Post-ICU Clinic Collaborative.

Within the THRIVE Collaborative, six general models of peer support are utilised and represented within this study: Community based models; Psychologist-led outpatient models; Models based within ICU follow-up clinics; Online models; Group-based models based within ICU and peer mentor models [2]. All programs involved in the THRIVE Post-ICU Clinic collaborative utilized a multi-disciplinary team approach.

## Data collection and generation

Data were collected via two separate, in-person focus groups with each collaborative. Sites not represented at the in-person meeting were purposively sampled and interviewed via video conference (n=2). Participants were informed of the focus groups prior to the Congress meetings and invited to participate on the day of the meeting.

A semi-structured interview guide was used (Supplementary File 1), with prompting questions. Questions were generated by examining previous literature and through iterative discussion with the research group. The guide was externally reviewed by a senior qualitative research expert. Data were audio-recorded and transcribed verbatim.

## Data analysis and rigor

Framework analysis was used to analyze the data [11]. The are seven stages to framework analysis: (1) transcription; (2) familiarization with the interview; (3) coding; (4) developing a working analytical framework; (5) applying the analytical framework; (6) charting data into the framework matrix; (7) interpreting the data [11].

Two researchers (KH, EH) undertook preliminary sweeps of the data to familiarize themselves with the content and develop initial coding. The data were grouped manually. The two researchers then jointly developed a working analytical framework [11]. The analytical framework with the major themes identified was rechecked against the preliminary analyses and raw data and final supporting quotes were selected (Supplementary File 2). To ensure rigor, regular crosschecking of analyses and data was undertaken by the research team (KH, JM, EH, CS). Full review of the analysis and presentation of the paper, was undertaken by an ICU family member, who also served as an author on this paper (BM).

The lead researchers (KH, JM, EH, CS) had monthly meetings to discuss any issues related to study conduct and analysis. The researchers were previously involved in the collaboratives and, therefore, known to members.

# Role of the funder

This analysis was funded by the SCCM. The scientific questions, analytic framework, data collection, and analysis were undertaken independently of the funder. The Executive Council of SCCM reviewed the manuscript and offered input regarding readability and presentation, prior to finalization.

The Consolidated Reporting of Qualitative Research (COREQ) checklist [12] was used for this study.

# Results

Overall, 28 participants contributed data: 11 and 15 participants from the peer support and post-ICU clinic focus groups, respectively (Table 1), and a further two peer support participants via follow-up interviews (unable to attend Congress). These contributors collectively represented various international sites (United States, United Kingdom, and Australia) and professions (nursing, medical, allied health).

Each focus group lasted between 60 and 90 min. A wide variety of experiences were available during the focus groups, with some sites having more prior experience of post-ICU programs, than others (Supplementary File 3). There was good representation from each THRIVE collaborative, with 11 out of 15 sites for the peer support collaborative and 10 out of 10 sites for the post-ICU clinic collaborative, present (Table 1). There was

**Table 1 Participant demographics** 

	ICU follow-up clinic (n = 15, participants)	Peer support (n = 13, participants)
Age (years), mean (SD)	41.3 (8.6)	44.1 (8.7)
Gender, n (%) male	7 (46.7)	3 (23.1)
Years of practice in criti- cal care (years) Mean (SD)	11.1 (6.9)	16.3 (10.4)
Discipline, n (%)		
Medical	8 (53.3)	6 (46.2)
Nursing	2 (13.3)	4 (30.8)
Pharmacist	4 (26.7)	1 (7.7)
Allied health	1 (6.7)	2 (17.4)
Sites represented, n (%) of total collaborative sites	10 (100)	11 (73) <sup>a</sup>

<sup>&</sup>lt;sup>a</sup> 11 out of 15 available sites were sampled, with no response for follow-up interview from the remaining four sites

representation from all prior recruitment waves of the THRIVE collaboratives.

The working analytical frameworks were first developed separately for follow-up clinics (Fig. 1) and peer support (Fig. 2); commonalities were further identified via framework analysis (Fig. 3). The quotes presented acknowledge the area where the information emerged from (Supplementary File 2).

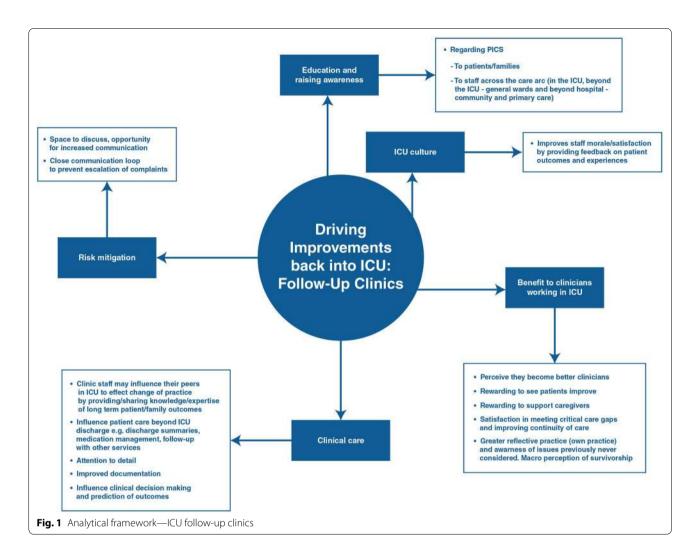
We identified five key mechanisms by which post-ICU activities have resulted in perceived improvements in care in the ICU: three at a formal/organizational level, and two at an informal/intra-clinician level (Fig. 3).

# Formal/organizational mechanisms to drive improvements back into the ICU

1. Identifying otherwise unseen targets for ICU quality improvement or education programs

Through caring for patients in post-ICU programs, participants noted aspects of care that mattered to patients and their families, but which they had not previously considered important. For example, they prompted colleagues to include important details in ICU discharge summaries:

Clinic: "When I'm on service, I scrutinize the discharge summaries to make sure they remember to say put a stop date for the anticoagulation, for the DVT."



Participants appeared better informed about supporting transitions of care. The informational needs of patients and families were identified and ideas to address the current gaps were discussed, such as creating an information packet on what to expect following ICU discharge, and providing information to the primary care provider:

Peer Support:"...A letter to the General Practitioner (GP) explaining that the patient has had an ICU stay and that they may be experiencing some aspects of Post Intensive Care Syndrome (PICS)."

Participants felt that by gaining a better understanding of patient and family ICU experiences in post-ICU settings, they could more readily identify areas for improved care in the ICU:

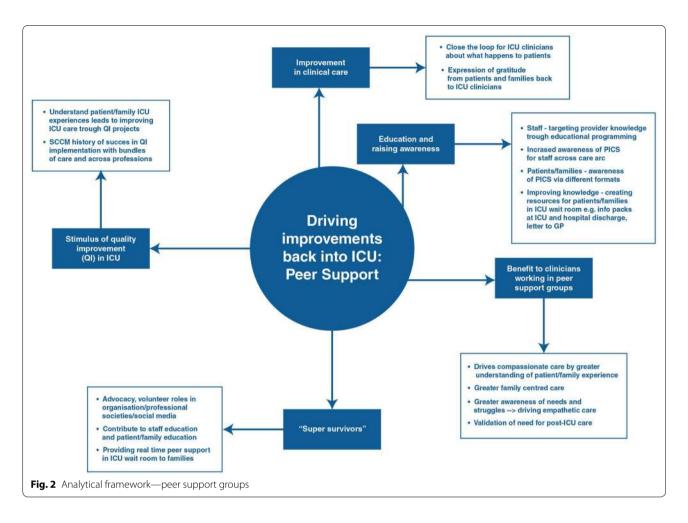
Peer Support: "...Little things like the 'all about me' boards. So I like to be called this, when I'm not in the intensive care unit I enjoy doing this, etc. I know a

lot of places had these already, we hadn't quite got to doing that till we got the feedback from patients and relatives."

#### 2. Creating a new role for survivors in the ICU

Some former patients and families were able to take on a role of "super survivor," where they adopt an advocacy role in professional societies and social media to raise awareness. The benefits of this were reported to be twofold: survivors advocate not only for themselves and their fellow patients, but also created impetus for ICU followup programs. Former patients and families in a "super survivor" role also contributed to staff education:

Peer Support: "One patient and his wife came to the hospital grand round and talked about their experiences and there were 150 people in the audience, and it was quite amazing that they did that... it was good for them, they enjoyed the experience,



they felt like they were helping, and giving something back."

Other former patients and families went on to adopt a volunteer role in the ICU, within the organization that cared for them:

Peer Support: "We've had one or two people volunteering for shifts on the ICU, just answering the door, and showing people in, that kind of stuff."

Others provided real-time peer support in the ICU waiting room:

Peer Support: "we've heard from our support group, that they can come back to the ICU and be that inspiring person."

Peer volunteer roles appeared to harness the altruistic nature of survivors who expressed gratitude for surviving their critical illness and the wish to give something back to the health service. This mechanism of "super survivor" roles not only closed the knowledge gap for clinicians, about what happens to patients after ICU,

but provided reassurance and hope for patients and families.

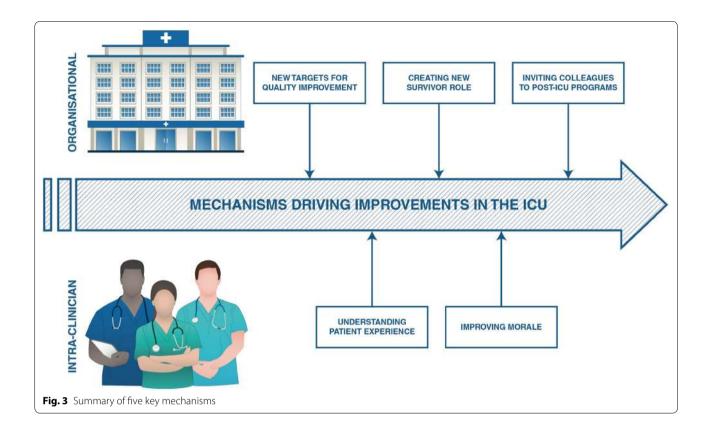
3. Educating ICU colleagues by having them visit the post-ICU program

Participants reported inviting peers to attend the post-ICU program to provide insights into how patients are cared for following ICU. This was reported to be a particularly helpful strategy for those sceptical about providing ICU follow-up services:

Clinic: "We've invited a lot of clinicians from the floor to see what we do and the things that we initiate through our own clinic... which is a great thing."

This knowledge was seen to inform clinical decision making in the ICU:

Clinic: "... Sometimes there's a push on palliative care, but sometimes you have a young otherwise healthy reversible disease and people are trying to push toward palliative care a little early... So



showing, I think from an education and trainee standpoint, that these folks actually do get out, maybe having them see some of the patients in the clinic too, but just at least giving the stories back to them is helpful."

Working in clinics also changed inter-professional dynamic in the ICU, helping emphasize the expertise possessed by other clinicians:

Clinic: "Our pharmacist has said it's been really helpful [working in clinic] because that affected his influence, his practice within the ICU and it's the same for us..."

# Informal/intra-clinician mechanisms to drive improvements back into the ICU

4. Changing clinician's own understanding of patient experience

Participants also described a direct individual themselves. They reflected on becoming better clinicians by gaining greater insights into patient experience: Clinic: "Seeing patients post-ICU has made me a better intensivist. It's not just the training; it's made me much more aware of things that I never gave thought to. Passing an NG tube and how excruciating that might be..."

Participants described a sense of fulfillment from working in clinics where they could deliver continuity of care, and partner with patients in helping them recover and improve their health:

Clinic: "The big plus for me has been watching people get better and watching them want to help."

Participants described how they were being able to recognize, anticipate and pre-empt patient and family needs post-ICU, during the ICU admission:

Peer Support: "We can start the ball rolling before they actually leave intensive care. If we can predict that they're going to be in for a while we get their benefits sorted."

It appeared that participants were surprised that families held relatively low expectations, and by extending small gestures of acknowledgments and help, they could achieve a reasonable level of impact:

Clinic: "...It's clearly a service that's required because every patient that I speak to, or relative, goes; I'm so pleased you phoned. There's a sort of relief that someone is there to help them, because there is nothing and they're just popped out in the ocean to sink or swim."

# 5. Improving morale

Participants discussed that programs offered the opportunity to close the feedback loop to ICU staff, about positive outcomes of challenging cases mitigated the risk of burnout for some clinicians:

Clinic: "Staff morale's been boosted because of the feedback to nurses, a lot of nurses have responded saying.....hearing they're making progress has been really helpful."

They also described they were more empathetic when they practiced in the ICU, with a greater focus on familycentered care:

Peer Support: "And just appreciating that you hear about the struggles of maintaining home, life, work, and transportation and how if it's an hour and a half to get to the hospital, and the financial burden as well. It just meant that in my conversations with updating families I ask now a lot earlier how far have you got to travel, do you want accommodation at the hospital?"

By delivering post-ICU programs, participants felt validated that there was a need for some form of longitudinal care:

Peer Support: "People are saying things like thank god I found this site, I'm so glad to know I'm not the only one. A lot of people are saying that I'm not alone; I thought I was going crazy, I'm so glad I found this forum."

# Discussion

Most evaluations of post-ICU care emphasize its patient and family-centered benefits, either via direct traditional patient care, or as a way to achieve closure for patients and families about unresolved questions from their illness. There has been much less focus on the ways in which such systems provide feedback to the health service and clinicians. We found five mechanisms by which post-ICU care is perceived by clinicians, to improve care within the ICU. Broadly, those mechanisms were: identifying new targets for quality improvement, creating new roles for survivors, educating ICU colleagues via visits to

post-ICU programs, understanding patient experience, and improving clinician morale. Overall, we found that post-ICU programs provide clinicians with a perspective that was not otherwise visible to teams when working only in the ICU.

Some of the practice changes that participants reported were transformational-for example, the integration of a new survivor volunteer role into the ICU and hospital setting. Yet many were incremental-elements that seem like common medical approaches. These elements had not been identified by the clinicians as part of their ongoing practice, but through interactions with patients after the ICU. This is consistent with literature in implementation science demonstrating ubiquitous challenges to implementing best practices [13]-including low tidal volume ventilation [14] and the administration of timely antibiotics [15]. The claim of this paper is not that engagement with post-ICU programs is necessary for these practice improvements to occur. Instead, post-ICU activities are an additional approach to drive practice improvements. In the view of study participants, engagement with post-ICU activities was an effective mechanism that drove improvements that may not have otherwise occurred. We did not find a consistent difference in our data between the mechanisms that came from clinician engagement with follow-up clinics as compared to peer support activities—the between institution variance was greater than the variance between these two types of activities, which frequently co-occur among these study participants. This suggests future research should not solely focus on specific post-ICU activities, but also develop feedback mechanisms for improving ongoing ICU care and measuring the impact of these activities on ICU care improvement.

A recurrent theme was that work in the post-ICU setting addressed contemporary workforce issues such clinician burnout and compassion fatigue [16], both directly (for those staffing the clinic) and indirectly (by providing feedback to others). There is growing evidence supporting the link between clinician wellbeing and patient experience [17, 18] with recent data demonstrating that burnout is associated with lower quality care and patient satisfaction [19]. These concepts are congruent with Safety-I and Safety-II theories, where "safety management should move from ensuring that 'as few things as possible go wrong' to ensuring that 'as many things as possible go right' and where people in the system are viewed as an asset to achieve system flexibility and resilience" [20, 21]. Given the challenges of mitigating burnout, this benefit may be of value to some hospital systems.

Of interest, none of the participants had developed a separate reporting mechanism back to the ICU. Rather they integrated post-ICU experiences as another data stream into existing (usually informal) ICU processes for uncovering opportunities for improvement. Systematic reporting mechanisms might offer yet further benefits and help understand the challenges of developing meaningful outcomes for patients. At present the literature in this field has focused on outcomes around health related quality of life and other individual level outcomes [22, 23]. This work should act as a catalyst for re-thinking outcomes; there may be other mechanisms by which ICU aftercare improves safety and effectiveness. However, this work examines clinician views in isolation; future work should explore this from a patient and caregiver perspective.

There are limitations to these data. The mechanisms perceived by clinicians have not been proven to be effective, nor directly measured, but should be. The post-ICU programs reported here were part of an international collaborative; programs run in isolation might have different effects. Although this unique international collaboration helped develop innovation generation in this area; it may be subject to bias as the participants are already motivated to conduct this work and improve care. We have used contemporary qualitative methods, including specific approaches to enhance reproducibility, such as a rigorous analytical process across an international team and extensive member-checking. Nonetheless, other interpretations may be possible.

### **Conclusions**

While the evidence for post-ICU programs has not been established [6, 22], these data suggest an appropriate evaluation should include other benefits to such programs beyond the specific enrolled patients. We identified five key mechanisms by which post-ICU care is perceived by clinicians to drive improvements in care in the ICU: at a formal/organizational level and at an informal/intra-clinician level). Intentional effort to optimize these mechanisms may drive further improvements in patient and family-centered care in the ICU.

# **Electronic supplementary material**

The online version of this article (https://doi.org/10.1007/s00134-019-05647-5) contains supplementary material, which is available to authorized users.

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# Author contributions

Conception and design: KH, JM, TIJ, MM, CS. Data Collection: KH, JM, LB, CS. Primary analysis: KH, JM, EH, CS. Analysis and interpretation: JM, KH, CS, EH, TIJ. Drafting and revising the manuscript for important intellectual content: ALL.

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#### Compliance with ethical standards

#### Conflicts of interest

No conflicts of interest declared by other authors.

# Role of the funder

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