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Carly Robinson  
*Glasgow Royal Infirmary, UK*

Elizabeth Hibbert  
*Western Health, Australia*

Anthony J. Bastin  
*St Bartholomew's Hospital, UK*

Joel Meyer  
*Guy's & St Thomas' NHS Foundation Trust, UK*

Ashley A. Montgomery-Yates  
*University of Kentucky, Ashley.Montgomery@uky.edu*

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### Authors

Carly Robinson, Elizabeth Hibbert, Anthony J. Bastin, Joel Meyer, Ashley A. Montgomery-Yates, Tara Quasim, Andrew Slack, Mark E. Mikkelsen, Theodore J. Iwashyna, Kimberly J. Haines, Carla M. Sevin, Joanne McPeake, and Leanne M. Boehm

OPEN

# An International Study Exploring the Experience of Survivors of Critical Illness as Volunteers Within ICU Recovery Services

Carly Robinson, BN<sup>1</sup>; Elizabeth Hibbert, B.Physiotherapy<sup>2</sup>; Anthony J. Bastin, MBBS, PhD<sup>3</sup>; Joel Meyer, BM, BCh, DM<sup>4</sup>; Ashley Montgomery-Yates, MD<sup>5</sup>; Tara Quasim, MBChB, MD<sup>1,6</sup>; Andrew Slack, MBBS, MRCP, EDIC, MD (Res)<sup>4</sup>; Mark E. Mikkelsen, MD, MSCE<sup>7</sup>; Theodore J. Iwashyna, MD, PhD<sup>8,9</sup>; Kimberley J. Haines, PhD, BHSc (Physiotherapy)<sup>2,10</sup>; Carla M. Sevin, MD<sup>11</sup>; Joanne McPeake, PhD, MSc, BN (Hons), RGN<sup>1,6</sup>; Leanne M. Boehm, PhD, RN, ACNS-BC<sup>12,13</sup>

**Objectives:** Many clinicians have implemented follow-up and aftercare to support patients following ICU. Some of this care is supported and facilitated by peer volunteers. There is limited contemporary work that has explicitly explored volunteer roles within ICU recovery services or the experience of volunteers undertaking these roles. We sought to explore the experience of survivors of critical illness, as volunteers,

involved in ICU recovery services and understand their motivation for undertaking these roles.

**Design:** Qualitative exploration using in-depth semistructured interviews. The study design used an inductive content analysis process. We also documented the roles that were adopted by volunteers in each site involved in the study.

**Setting:** Patients and caregivers were sampled from seven sites across three continents.

**Patients and Subjects:** Patients and caregivers who had adopted peer-volunteering roles were undertaken.

**Interventions:** None.

**Measurements and Main Results:** Twelve patient and caregiver peer volunteers were interviewed. Four key themes were identified. These themes related to the experience of volunteers within ICU recovery services and their motivation for undertaking these roles: 1) self-belief and acceptance, 2) developing peer support, 3) social roles and a sense of purpose, and 4) giving back. Overwhelmingly, participants were positive about the role of the volunteer in the critical care setting.

**Conclusions:** Peer volunteers undertake a variety of roles in ICU recovery services and during recovery more generally. These roles appear to be of direct benefit to those in these roles. Future research is needed to develop these roles and fully understand the potential impact on the service, including the impact on other patients.

**Key Words:** critical care; rehabilitation; volunteer; long-term outcomes

<sup>1</sup>Glasgow Royal Infirmary, NHS Greater Glasgow and Clyde, Glasgow, United Kingdom.

<sup>2</sup>Department of Physiotherapy, Western Health, Melbourne, VIC, Australia.

<sup>3</sup>Department of Perioperative Medicine, St Bartholomew's Hospital, Barts Health NHS Trust, London, United Kingdom.

<sup>4</sup>Guy's & St Thomas' NHS Foundation Trust, London, United Kingdom.

<sup>5</sup>Division of Pulmonary, Critical Care and Sleep Medicine, University of Kentucky, Lexington, KY.

<sup>6</sup>School of Medicine, Dentistry and Nursing, University of Glasgow, Glasgow, United Kingdom.

<sup>7</sup>Division of Pulmonary, Allergy, and Critical Care Medicine, Hospital of the University of Pennsylvania, Philadelphia, PA.

<sup>8</sup>Department of Medicine, Division of Pulmonary and Critical Care, University of Michigan, Ann Arbor, MI.

<sup>9</sup>Center for Clinical Management Research, VA Ann Arbor Healthcare System, Ann Arbor, MI.

<sup>10</sup>School of Physiotherapy, The University of Melbourne, VIC, Australia.

<sup>11</sup>Department of Medicine, Division of Allergy, Pulmonary, and Critical Care Medicine, Vanderbilt University Medical Center, Nashville, TN.

<sup>12</sup>School of Nursing, Vanderbilt University, Nashville, TN.

<sup>13</sup>Cognitive Impairment, Brain dysfunction, and Survivorship (CIBS) Center at Vanderbilt, Nashville, TN.

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“postintensive care syndrome” (PICS) (6). To counteract the problems associated with PICS, some clinicians have implemented ICU aftercare programs (7).

Research has evaluated the various forms of aftercare that ICU patients and caregivers require in the short, medium, and long terms (8, 9). Strategies implemented vary in their delivery, from formal hospital outpatient clinic appointments with a traditional doctor-patient interaction; longer multidisciplinary sessions with input from the wider care team such as physical therapists, pharmacists, and psychologists; and clinics and peer support groups (10). Peer support can be provided in various forms including support groups for patients and caregivers run by medical professionals or it through the use of patient and caregiver volunteers who act as “role models” (11). Many of these peer support groups and clinics rely on survivors and their caregivers as volunteers (hereafter described as peer volunteers collectively), who are further along the recovery trajectory, to provide insight and reassurance.

Significant literature exists on the volunteer experience in cancer and care of the elderly settings (12). In the existing literature, the benefits of volunteering roles are portrayed positively and provide benefits for both the volunteers and the patients (13). However, there is limited contemporary work that has explicitly explored volunteer roles in the ICU recovery setting or the experience of volunteers undertaking these roles.

## METHODS AND MATERIALS

### Aim

This international study sought to explore the experience of volunteers within ICU recovery services internationally and their motivation for undertaking these roles to allow for further service development and research evaluation.

### Design

We chose qualitative inquiry rather than a quantitative approach as we wished to hear participants describe their experiences in sufficient detail, so as to understand their experience fully.

### Sample/Participants

Sites involved in this study were part of the Society of Critical Care Medicine’s (SCCM) THRIVE program. THRIVE was established by the SCCM in 2015 to bring together critical care clinicians who were using ICU follow-up clinics and peer support models to improve patients’ and family members’ outcomes. The SCCM’s THRIVE program worked as an international learning collaborative, and it had a broad range of hospitals involved, delivering diverse programs of work. Its aim was to generate learning and encourage collaboration.

Peer volunteers who took part in these recovery programs or who were actively volunteering in other areas of ICU practice were purposively sampled to take part in semistructured interviews. All participants were either ICU survivors or caregivers of ICU survivors. Participants were approached by local clinicians in the area and asked if they would be willing to participate in the research. Volunteers were then contacted by the primary research team who undertook an in-depth semistructured interview with the

participant. No volunteer declined to participate in the study. We deliberately included sites in this study, which we knew had peer-volunteering roles in place. We recruited until data saturation was achieved (through consensus).

Inclusion criteria were patients older than 18 years and individuals with adequate English language skills to participate. Exclusion criteria were significant neurologic/cognitive impairment and inpatient status in a hospital/rehabilitation setting.

### Data Collection

Three researchers undertook the interviews. An interview schedule was created from previous research in the field and through an iterative process with the research team (**Supplemental Digital Content**, <http://links.lww.com/CCX/A419>). All researchers involved in the interview process discussed the interview schedule in advance to ensure consistency in the approach taken for data collection. Some of the researchers were known to the participants of the interviews through their direct clinical care role. Data were audio-recorded and transcribed verbatim. Interviews were undertaken via telephone or in person. Interviews took place between July 2018 and February 2019. All interviews were undertaken in English.

### Ethical Considerations

The study design and protocol were approved by the Western Health Low Risk Human Research Ethics Panel (Australia), the University of Vanderbilt Institutional Review Board (U.S. coordinating site), and the South West (Cornwall and Plymouth) Research Ethics Committee for all U.K. sites.

### Data Analysis

The study used an inductive content analysis (14). Five key steps were included in the data analysis process (**Table 1**). First, the primary analysis team (C.R., J.M., L.M.B.) reviewed the data to familiarize themselves with the content and to develop initial open coding. No preset or a priori codes were utilized to group the data. Second, the team built two coding sheets and freely developed categories for data analysis. After the coding sheets were generated, the data were grouped under higher order headings. This third

**TABLE 1. Five Stages of the Data Analysis Process**

Stage	Process
One	Preliminary sweeps of data Development of initial coding
Two	Two coding frameworks created
Three	Initial coding built under key themes Iterative checking of codes across the interview transcripts
Four	Definition and classification of key themes Creation of conceptual frameworks
Five	Extraction of quotes Review of conceptual models

step collapsed codes that were similar or dissimilar to higher categories. At this stage, we also explicitly sought differences in the data from an individual role perspective, as well as site differences. Fourth, three researchers (C.R., J.M., L.M.B.) defined and classified the key themes. The final stage “abstraction” created the overarching themes of this data and linked supporting quotes with themes. The lead researchers (C.R., J.M., L.M.B.) had monthly meetings to discuss any issues related to study conduct and analysis.

## Rigor

The Consolidated Reporting of Qualitative Research checklist (15) was used for this study.

The principal investigators were all experienced researchers who were familiar with carrying out semistructured interviews. The researchers approached the peer volunteers ahead of time and gave them an opportunity to ask any questions. Informed consent was obtained from all participants and the researchers provided assurances that any ongoing treatment or care would not be affected by participating in the interview.

Steps were taken to ensure trustworthiness of the data obtained; four main criteria were applied (16). First, to ensure credibility, member checking was undertaken. These involved participants receiving copies of the transcribed interviews to identify any inconsistencies or to highlight any interpretations or accounts made by the research team that they may deem to be inaccurate (17).

Three researchers (C.R., J.M., L.M.B.), all experts in this field, analyzed transcripts independently to look for emerging themes and then came together to discuss their individual findings. To ensure the transferability of the findings, data were peer-reviewed by a researcher external to the main analysis team (18). This helped to reduce the possibility of researcher bias and challenged the robustness of emerging themes (18). Any difference of opinion resulted in the original data being reexamined until an agreement was reached.

Finally, to ensure both dependability and confirmability, an audit trail was established. This process helped external peer reviewers establish the rigor of the study by providing details of data analysis and information on some of the decisions that led to the findings (19).

## RESULTS

### Participant Characteristics

Twelve peer volunteers from seven international sites were interviewed; seven from three U.K. hospitals (58%); two from Australia (17%), and three from three hospital sites in the United States (25%). Nine participants had been patients in the ICU and three participants had been caregivers of ICU patients. Interviews took place between July 2018 and February 2019.

The median age of the 12 peer volunteers was 59 years (interquartile range, 49–67 yr) and 6 (50%) were female.

The participating sites and the role of the peer volunteer in each of these sites are shown in **Table 2**. Peer volunteers undertook a variety of roles, including support with direct care, supporting the facilitation of peer led groups and providing peer support to other patients. Peer volunteers also adopted roles that helped raise the profile of the ICU survivor population more generally, including presenting at inhouse study days and conferences. There were a

number of pathways into these roles for peer volunteers, including taking up activities in established programs and events. Other peer volunteers created and helped developed roles to improve outcomes within specific contexts and environments.

Four key themes were identified from the 12 interviews undertaken (**Fig. 1**). These themes related to the experience of peer volunteers within ICU recovery services and their motivation for undertaking these roles: 1) self-belief and acceptance, 2) developing peer support, 3) social roles and a sense of purpose, and 4) giving back. Illustrative quotes related to these themes are shown in **Table 3**.

### Self-Belief and Acceptance

One reason why individuals engaged with these roles was reflected in the outcome of the activity: the development and promotion of self-belief and acceptance. One peer volunteer, for example, described how they had lost confidence following critical illness and how their role within the ICU follow-up service had helped rebuild this:

I'd lost my confidence, my self-respect, I'd lost everything... then I come to the clinic and I start to get my self-confidence back, start to realise that there is... I've got a future you know, and its helping.

Other participants described how engagement in volunteering activities had helped them come to terms with their illness. For example, one volunteer described how this role had helped them accept, “a new norm” and how supporting others had led them to move past anger and frustration:

It really helped me come to terms with things, some things I won't ever be able to do again but...I just get on with it now

### Social Roles and a Sense of Purpose

There were differences in why participants took part in volunteering activities and how volunteering roles would support the transition back to previous (pre-ICU) activities. For some, volunteering roles were a transition back to paid employment:

I was determined to go back to work, or I thought I could.. I'd say I'm trying to work but all I'm doing is sitting at my desk, I was afraid they was gonna fire me.. And so Dr X said I might have a volunteer role for you just hang tight.. and then I found my purpose

Others discussed the benefits of peer volunteer roles in relation to psychologic recovery and social reintegration:

I felt so relaxed, so at ease. Even sometimes I was just making coffee, making tea, clearing up. It gave me a purpose

Although there were differences on expected outcomes in the interviews, the key mechanism for reintegrating into previous roles through volunteering activities was similar—the sense of purpose participants gained:

They always made me feel welcome and that was lovely, I think that was the main part, I felt useful again. It made me feel useful being a volunteer

Another key mechanism, by which volunteering roles appeared to bridge the gap between previous activities and current status, was through the reduction in social isolation which many

**TABLE 2. Role of Volunteer Within the Service**

Site Number	Country	Overarching Role of the Volunteer	Location of Volunteering
1	United Kingdom	Supports patients attending ICU recovery clinic on a weekly basis. They support the running of a "café area" and provide informal support for patients and caregivers. Roles can be filled by either a patient or caregiver  Attendance at patient and staff days. Involved in publicly speaking to the audiences about ICU experience and recovery	Hospital clinic setting  Staff engagement events
2	United Kingdom	Patient representative on national ICU professional network  Supports the running of in person support groups  Delivery of sessions to staff about ICU patient experiences	Attendance at committee meetings.  Participation in online platforms
3	United Kingdom	Attendance at patient and staff days. Involved in publicly speaking to the audiences about ICU experience and recovery  Attendance at "hospitalwide meetings" to speak to wider healthcare community about ICU experiences and recovery	In hospital setting  Staff engagement events
4	United States	Supports patients and family members in the ICU. In conjunction with social worker, helps in identifying patients for ICU Recovery Clinic. Involved in publicly speaking to clinical and lay audiences about ICU experience and recovery. Created mobile app to help with ICU patient communication	Inhospital setting  Independent developer/consultant  Attendance at committee meetings
5	United States	Supports the running of in person support groups  Supports patients and family members in the ICU	Inhospital setting
6	United States	Supports patients and family members in the ICU Recovery Clinic and support groups. Involved in public speaking to clinical audiences about ICU experience and recovery. Reviewer of clinical grant applications for ICU research	Hospital clinic setting
7	Australia	Involved in public speaking to clinical audiences about ICU experience and recovery such as hospital-based quality improvement forums and statewide research conferences. Reviewer of clinical grant applications and articles for ICU research. Involvement in codesign activities	Staff engagement events

participants felt following critical illness. Volunteering roles helped support healthy social engagement:

You get more comfortable through time, and it became like a little community, which wasn't a chore, it was a joy to participate.

### Developing Peer Support

The benefits of peer support were mentioned in every interview. Peer support benefited the participants in several ways. It helped participants put their own progress in context; participants could contextualize their progress through speaking to patients who were earlier in their recovery trajectory:

It makes you sort of appreciate what you can do, you've got to appreciate what you can do and not what you can't do and I think that helped me as a volunteer as well because there was other people in the same boat as me and maybe I came to terms with it a wee bit better

Peer volunteers could continue to enhance their own recovery status with these interactions. Peer support helped patients normalize their feelings, especially around ongoing psychologic issues that may have emerged from critical illness:

...you think you are in a bad place and then you hear some of the other people who have went through different things than I went through, you know, and I thought, 'my God I'm not really as bad as I thought I was'.

### Giving Back

The final theme that was generated was around participants "giving back." This sense of altruism was multifaceted; participants described how it was driven by giving back to the service and also by supporting other patients. In relation to giving back to the service, participants described how they wanted to help the service (namely, ICU) and the staff who supported them:

I felt as if I was doing something. I was giving something back for people, for the National Health Service

In parallel, participants also described that by being included, they had the opportunity to support others and enhance recovery:

As a volunteer it was sort of talking to other patients...just trying to reassure them and maybe if they wanted to talk about their experience or if they wanted to know my experiences and what I got out of the recovery service

Finally, there was a sense of community, which emerged from the interviews. Participants were keen to raise the profile of ICU survivorship. Volunteering roles offered a platform to help support patients at a population level, as well as at an individual patient level:

You are speaking to just fellow patients and fellow patients' families and things like that, discussions and things it takes a lot, it takes a weight off, you know. You are not the only one, so you're not alone. And that was brilliant for me

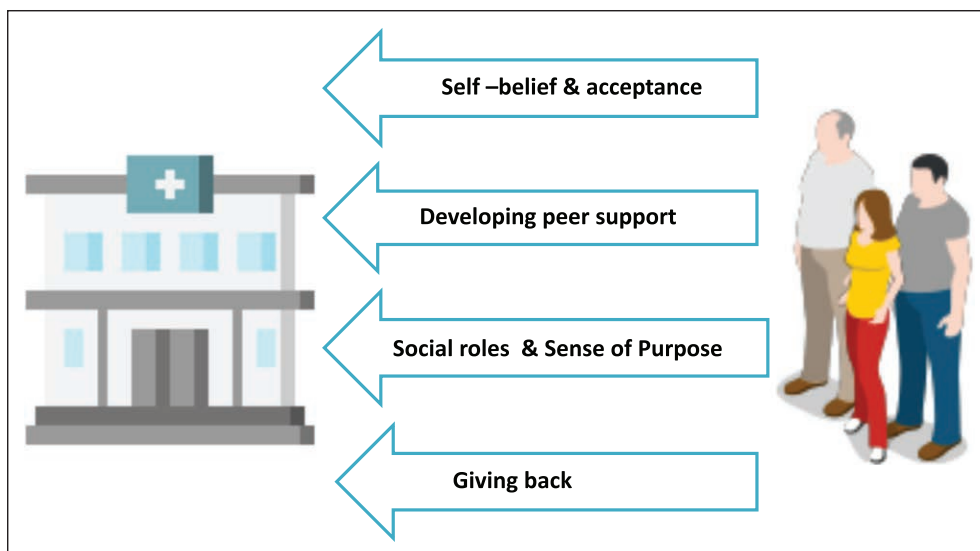


Figure 1. Visual representation of key themes.

## DISCUSSION

This study provides contemporary international data that document the involvement of peer volunteers in ICU recovery services. It has shown that these roles bring multiple benefits to those involved. These benefits include ongoing peer support, providing

a sense of purpose and acceptance and supporting the transition back to previous social roles. We found no difference in these perceived benefits across different types of roles, although the motivation for undertaking volunteering roles appeared to differ between the participants.

This study is consistent with previous research from other specialities, demonstrating the positive benefits of volunteering roles, especially in relation to peer support (20). Peer support was bidirectional; participants themselves benefited from peer support and they benefited from delivering peer support to other patients. As an important concept in the critical care field, peer support is believed to offer external and internal validations of progress

and provides patients with informal support networks to help normalize symptoms directly related to problems following critical illness (11, 21–23). As yet, there is little evidence that demonstrates the effectiveness of peer support programs (of any type) in this population (24). Research exploring this concept is warranted.

## TABLE 3. Themes Generated, Alongside Supporting Quotes

Theme	Supporting Quote
Self-belief and acceptance	<p>-I'd lost my confidence, my self-respect, I'd lost everything... then I come to the clinic and I start to get my self-confidence back, start to realise that there is... I've got a future you know, and its helping.</p> <p>It really helped me come to terms with things, some things I won't ever be able to do again but those I can I just get on with it now</p> <p>(through volunteering) there were some things that I have been able to do that have, that I'm very grateful for and if you were to ask me, are you sorry that you got sick? I would say no, I've accepted it</p>
Bridging the gap to previous activities	<p>I was down and depressed, and a lot of things, actually was crazy at one point for the first year and a half after discharge. And then I found my purpose. And my purpose is ICU.</p> <p>I felt so relaxed, so at ease. Even sometimes I was just making coffee, making tea, clearing up. It gave me a purpose</p> <p>They always made me feel welcome and that was lovely, I think that was the main part, I felt useful again. It made me feel useful being a volunteer</p> <p>I wasn't as dependent on him (caregiver) then you know? I don't like being dependent on anybody! I'm a very independent person and I think to get back to the stage where I could do these things for myself again, I think he realised that's what I really needed</p>
Developing peer support	<p>It makes you sort of appreciate what you can do, you've got to appreciate what you can do and not what you can't do and I think that helped me as a volunteer as well because there was other people in the same boat as me and maybe I came to terms with it a wee bit better</p> <p>you think you are in a bad place and then you hear some of the other people who have went through different things than I went through you know and I thought my God I'm not really as bad as I thought I was</p> <p>Other people, like you, know what you've gone through and understand it, it actually takes away some of that isolation</p> <p>I'm meeting other people who have been in the same boat as me as a relative so again you can talk to people</p>
Giving back	<p>I felt as if I was doing something. I was giving something back for people, for the National Health Service</p> <p>As a volunteer it was sort of talking to other patients....just trying to reassure them and maybe if they wanted to talk about their experience or if they wanted to know my experiences and what I got out of the recovery service</p> <p>You are speaking to just fellow patients and fellow patients' families and things like that, discussions and things it takes a lot, it takes a weight off you know. You are not the only one, so you're not alone. And that was brilliant for me</p>

In this purposively sampled population, participants undertook volunteering roles for different reasons. Some saw volunteering roles as a bridge back to employment, whereas others adopted these roles with the aim of transitioning back to former social roles and to “give back” to the health service. It is important to understand these differences when examining ICU recovery services as a whole; patients may need support to get back to work and support for financial welfare during recovery. There is emerging evidence that return to employment and socioeconomic problems are common in ICU survivors and their loved ones; however, there is limited evidence examining interventions to ameliorate these issues (5, 25). These issues are important when examining large-scale interventional research in this area, which to date has shown limited effectiveness in improving health related quality and life and functional outcomes in this patient group (10). No trial to date has explicitly sought to integrate health and social care to improve specifically long-term outcomes in this group. This should be considered in future research in this area.

This study has strengths: it has carefully documented peer volunteer roles being undertaken by former patients and caregivers within ICU recovery services internationally. Furthermore, it has used rigorous, reproducible methodology to be undertaken for analysis. However, there are limitations to the data presented. The ICU recovery services that peer volunteers were involved with were part of an international collaborative and may not fully represent the views of all volunteers internationally nor capture all volunteer roles (e.g., patient and family advisory council member as volunteer role). We also did not look at the individual pathway for those undertaking volunteering roles (e.g., how far forward each patient was in their recovery). This may have affected their views and ability to undertake specific roles. We did not include all volunteers in the sites studied, as such there may be experiences that have not been represented within this research. Furthermore, we examined the experience of patients already in volunteering roles; therefore, we likely captured those who had benefitted from volunteering and potentially missed participants with less favorable experiences. Finally, our sample size is small and is unable to determine differences in experiences across socioeconomic status, ethnicity, and other important demographics. Future research is needed to understand fully the potential outcomes of volunteering roles in this context.

## CONCLUSIONS

This international study has examined the experiences of individuals undertaking peer-volunteering roles in the ICU environment. These roles appear to be of direct benefit to those adopting them. Future research is needed to develop these roles and fully understand the potential impact on ICU recovery services, including the patients receiving the intervention.

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Address requests for reprints to: Joanne McPeake, PhD, MSc, BN (Hons), RGN, Room 2.70, New Lister Building, NHS Greater Glasgow and Clyde, Glasgow G4 0SF, United Kingdom. E-mail: [joanne.mcpeake@glasgow.ac.uk](mailto:joanne.mcpeake@glasgow.ac.uk)

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