An Unbelievable Ordeal: The Experiences of Adult Survivors Treated with Extracorporeal Membrane Oxygenation

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**Recommended Citation**

Knudson, Krista A.; Funk, Marjorie; Redeker, Nancy S.; Andrews, Laura K.; Whittemore, Robin; Mangi, Abeel A.; and Sadler, Lois S., "An Unbelievable Ordeal: The Experiences of Adult Survivors Treated with Extracorporeal Membrane Oxygenation" (2022). *College of Nursing Faculty Research and Publications*. 948.  
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An Unbelievable Ordeal: The Experiences of Adult Survivors Treated with Extracorporeal Membrane Oxygenation

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Abstract

Background
Extracorporeal membrane oxygenation (ECMO) is a rescue treatment option for adult patients with severe cardiac dysfunction or respiratory failure. While short-term patient outcomes, such as in-hospital mortality and complications, have been widely described, little is known about the illness or recovery experience from the perspectives of survivors. Subjective reports of health are important indicators of the full, long-term impact of critical illness and treatment with ECMO on survivors’ lives.

Objective
The objective of this study was to describe the experiences and needs of adults treated with ECMO, from onset of illness symptoms through the process of survivorship.

Methods
This study was guided by the qualitative method of interpretive description. We conducted in-depth, semistructured interviews with 16 adult survivors of ECMO who were treated at two participating regional ECMO centres in the northeast United States. Additional data were collected from demographic questionnaires, field notes, memos, and medical record review. Development of interview guides and data analysis were informed by the Family Management Style Framework. Qualitative data were analysed using thematic analysis techniques.

Results
The sample (n = 16) included 75% male participants; ages ranged from 23 to 65 years. Duration from hospital discharge to interviews ranged from 11 to 90 (M = 54; standard deviation = 28) months. Survivors progressed through three stages: Trauma and Vulnerability, Resiliency and Recovery, and Survivorship. Participants described short- and long-term impacts of the ECMO experience: all experienced physical challenges, two-thirds had at least one psychological or cognitive difficulty, and 25% were unable to return to work. All were deeply influenced by their own specific contexts, family support, and interactions with healthcare providers.

Conclusions
The ECMO experience is traumatic and complex. Recovery requires considerable time, perseverance, and support. Long-term sequelae include impairments in cognitive, mental, emotional, physical, and social health. Survivors could likely benefit from specialised posthospital health services that include integrated, comprehensive follow-up care.

Keywords
Critical care, Critical illness, Extracorporeal membrane oxygenation, Long-term outcomes, Physical health, Post-intensive care syndrome, Mental health, Survivorship

1. Introduction
Extracorporeal membrane oxygenation (ECMO) provides cardiopulmonary support for patients with cardiogenic shock/cardiac arrest or severe acute respiratory distress refractory to conventional therapy. The two primary configurations of ECMO are veno-venous (VV) and veno-arterial (VA); both provide oxygen and remove carbon...
dioxide, but only VA ECMO provides haemodynamic support. Patients may be supported on ECMO until recovery, insertion of mechanical circulatory device (e.g., left ventricular assist device [LVAD]), or transplant.

Sixty percent of VV ECMO and 43% of VA ECMO patients survive to hospital discharge. ECMO is associated with high rates of morbidity (e.g., bleeding, infection, acute kidney injury). Long-term survival (2–5 y after successful weaning from ECMO or hospital discharge) ranges from 71% to 76%. Adult survivors of ECMO-related illnesses commonly experience diminished health-related quality of life and limitations in physical, mental, functional, and social health. Therefore, to prepare for discharge and long-term healthcare needs, it is important to consider subjective indicators of health and long-term function in the assessment of interventions.

To date, only two qualitative studies address the lives of adult ECMO survivors. In their report of the experience of 10 adult survivors, 1 y after hospital discharge, Tramm et al. described the following themes: dealing with crisis, critical care, memory, role of significant others, and existence today and tomorrow. Most survivors described rapid deterioration in health and a period of crisis as they became critically ill and required ECMO treatment. The most frequently reported experience for those participants was severe physical deconditioning. Most survivors experienced episodes of delirium and maintained incomplete memories of the ICU period. Chen et al. conducted interviews with 14 Taiwanese ECMO survivors at 3, 6, 9, and 12 months after hospital discharge. Physical complications were common and contributed to psychological problems and social isolation. Recovery was particularly slow for the first 6 months after discharge. No participants returned to work until at least 4 months after discharge. Many participants sought to make health a priority and incorporated complimentary or traditional medicine therapies into their lives. Adapting to disability after hospital discharge was challenging and many emphasised the importance of their social support networks for support.

Our investigation was part of a larger qualitative study to understand the ECMO experience from the perspectives of survivors and family members. Description of the experiences of family members will be provided in a separate report. The purpose of the present study was to describe the experiences and needs of adults treated with ECMO, including the following: (i) initial onset of symptoms through recovery and survivorship; (ii) impact on physical, psychological, cognitive, functional, and social well-being; and iii) interactions with healthcare providers.

2. Methods

2.1. Study design
We used the qualitative approach of interpretive description, which blends techniques such as reflective and critical examination of diverse types of qualitative data to generate clinically relevant knowledge. We used the Family Management Style Framework (FMSF) to develop our interview guide and inform data analysis as it describes ways in which members of a family, including the ill person, respond to and manage health-related challenges. In this framework, family responses are shaped by four important factors: (i) their particular sociocultural context (Contextual Influences); (ii) how members of a family view the ill person and the illness (Definition of the Situation); (iii) family philosophies, goals, and priorities that shape how families manage the illness (Management Behaviours); and (iv) expectations for the future (actual or perceived) that influence family management behaviours and subsequent definition of the situation (Perceived Consequences).

2.2. Sample and setting
Study participants were adults (aged ≥18 y) treated with ECMO at two regional ECMO centres at urban academic medical centres in the northeast United States. Eligible participants were at least 1-month post-hospital discharge and could speak and write in English. Recruitment strategies at each site were determined by clinical site coordinators. At site one, most participants were recruited for the study by letters mailed to their homes.
Participants were recruited at site two by telephone call and letter by the site coordinator. We initially used purposive sampling to recruit survivors of ECMO treatment at both sites, including factors such as demographic characteristics and indication for ECMO treatment. Subsequently, we used theoretical sampling based on emerging findings to ensure adequate representation of important themes.\textsuperscript{15} Using concurrent data collection and analysis, we determined sample size when we reached data saturation.\textsuperscript{15} Stipends ($20) were provided for study participation.

2.3. Data collection and analysis
Interviews were completed by KAK in single-day sessions at locations convenient to participants, usually their homes. Before study commencement, no relationship existed between KAK and participants. On the day of the interview, KAK shared with participants her motivations for undertaking this research. Participants completed demographic questionnaires and in-depth, semistructured interviews. In all but one case, survivors were interviewed alone and separately from family members. The interview guide (Appendix A), informed by the FMSF, included open-ended questions and follow-up probes.\textsuperscript{18} We asked participants to describe what happened from the time they first became sick through the periods of intensive care unit (ICU)/ECMO treatment and recovery. Field notes documented contextual information,\textsuperscript{19} and research memos were used to describe patterns and identify potential themes during the analysis.\textsuperscript{20} Interviews were audio recorded, transcribed verbatim, checked for accuracy, and deidentified. Data from interviews, field notes, and memos were managed using Atlas.ti 7© Windows (Atlas.ti Scientific Software Development GmbH, Berlin).\textsuperscript{21}

We used thematic analysis to analyse our data.\textsuperscript{22} To assure consistency in meaning and application of codes, two investigators (KAK and LSS) inductively coded several transcripts independently to develop the coding manual. They independently applied the coding structure to six transcripts, compared codes, and arrived at consensus with any coding disagreement. They arrived at 80% intercoder agreement\textsuperscript{23} which then allowed KAK to continue with coding the remainder of transcripts.\textsuperscript{24} The final coding structure included 22 overarching codes and 108 subcodes. They identified patterns within the data, defined and refined themes, and developed thematic maps. Thematic saturation was determined when additional data did not lead to any new themes; KAK conducted one additional interview to ensure saturation of codes and themes. Additional data from field notes and memos kept during interviews and coding were also analysed. As recommended for reporting qualitative research,\textsuperscript{25}, \textsuperscript{26}, \textsuperscript{27} descriptors connoting indeterminate quantity are operationally defined as “most” occurs in >75% of participants, “many” occurs in >50%, “some” occurs in >25%, and “few” occurs in two or three participants.

Medical record reviews were completed after interviews and included data relevant to hospitalisations during the period of ECMO treatment (e.g., indication, configuration, and duration of ECMO; ICU and hospital lengths of stay; ICU admission source; short-term complications).

2.4. Rigour
We used multiple strategies to ensure study rigour.\textsuperscript{28} We established credibility by using theoretically driven sampling, prolonged engagement, and triangulation (of data sources, method, and investigators). We completed member checking with 10 participants, who endorsed the findings and suggested several minor edits, which were incorporated in the final report. We relayed our results using thick description, which enhances potential for transferability of these findings to other contexts or populations. Dependability and confirmability were assured with our audit trail, field notes, and memos (reflexive, theoretical, and methodological). Data were analysed by two authors: one experienced in clinical care of adults treated with ECMO (KAK) and one an experienced qualitative researcher (LSS).
2.5. Ethical considerations
This study was approved by the university institutional review board and the institutional review boards at both participating institutions. All participants provided written informed consent before data collection.

3. Results
Forty-nine survivors were invited to participate; 16 were enrolled (Appendix B). Interviews were completed in person ($n=15$) or over the telephone ($n=1$). The mean duration of interviews was 107 (standard deviation = 68; range 32–335) minutes.

3.1. Participant characteristics
Sixteen survivors underwent 17 runs of ECMO support between 2010 and 2017 (Table 1). The sample included 75% male and 100% white and non-Hispanic participants. Their ages ranged from 23 to 65 y. All were treated with a combination of medications associated with development of delirium and/or posttraumatic stress.39,40 Immediately after the ECMO-related illness, one person retired earlier than planned and three participants were permanently physically disabled.

Table 1. Demographic and clinical characteristics of survivors ($N=16$)

<table>
<thead>
<tr>
<th>Survivor characteristic</th>
<th>$M$ ($SD$); range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (y) at time of ECMO treatment</td>
<td>50.3 (13.0); 23-65</td>
</tr>
<tr>
<td>Duration of ECMO treatment (days)</td>
<td>6.5 (4.3); 2-19</td>
</tr>
<tr>
<td>ICU LOS (days)</td>
<td>26.8 (13.8); 7-59</td>
</tr>
<tr>
<td>Hospital LOS (days)</td>
<td>42.2 (20.2); 17-84</td>
</tr>
<tr>
<td>Duration from hospital discharge to interview (months)</td>
<td>53.7 (27.7); 11.0–90.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Survivor characteristic</th>
<th>$N$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male sex</td>
<td>12 (75.0%)</td>
</tr>
<tr>
<td>White race</td>
<td>16 (100%)</td>
</tr>
<tr>
<td>Non-Hispanic ethnicity</td>
<td>16 (100%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>&lt;$ High-school diploma</td>
<td>1 (6.2%)</td>
</tr>
<tr>
<td>High-school diploma</td>
<td>5 (31.2%)</td>
</tr>
<tr>
<td>2–4 years college</td>
<td>7 (43.8%)</td>
</tr>
<tr>
<td>Graduate school</td>
<td>3 (18.8%)</td>
</tr>
<tr>
<td>Work status at time of interview</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>6 (37.5%)</td>
</tr>
<tr>
<td>Part-time</td>
<td>3 (18.8%)</td>
</tr>
<tr>
<td>Disabled$^b$</td>
<td>3 (18.8%)</td>
</tr>
<tr>
<td>Retired</td>
<td>4 (25.0%)</td>
</tr>
<tr>
<td>Configuration/indication for ECMO</td>
<td></td>
</tr>
<tr>
<td>VV: respiratory failure$^c$</td>
<td>2 (12.5%)</td>
</tr>
<tr>
<td>VA: cardiogenic shock/arrest$^d$</td>
<td>14 (87.5%)</td>
</tr>
<tr>
<td>ICU admission source</td>
<td></td>
</tr>
<tr>
<td>ECMO centre ED</td>
<td>7 (43.8%)</td>
</tr>
<tr>
<td>ECMO centre via scheduled appointment (clinic or procedure)</td>
<td>2 (12.5%)</td>
</tr>
<tr>
<td>Transfer from another hospital</td>
<td>7 (43.8%)</td>
</tr>
<tr>
<td>Short-term complications</td>
<td></td>
</tr>
<tr>
<td>Bleeding and/or coagulopathy requiring transfusion</td>
<td>12 (75.0%)</td>
</tr>
<tr>
<td>Infection (i.e., pneumonia, UTI, thrush, concern for CNS aspergillosis)</td>
<td>11 (68.8%)</td>
</tr>
<tr>
<td>Renal injury</td>
<td>8 (50.0%)</td>
</tr>
<tr>
<td>Condition</td>
<td>Count (Prevalence)</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>--------------------</td>
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<tr>
<td>Required CVVH</td>
<td>3 (18.8%)</td>
</tr>
<tr>
<td>Other end-organ damage (i.e., mesenteric ischaemia, hepatic dysfunction)</td>
<td>5 (31.3%)</td>
</tr>
<tr>
<td>Eye problems (i.e., uveitis, conjunctivitis, ocular/retinal damage)</td>
<td>3 (18.8%)</td>
</tr>
<tr>
<td>Delayed wound healing (i.e., ECMO cannulation site wound dehiscence,</td>
<td>3 (18.8%)</td>
</tr>
<tr>
<td>necrosis of toes requiring hyperbaric oxygen treatment)</td>
<td></td>
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</tbody>
</table>

Note: CNS = central nervous system; CVVH = continuous veno-venous haemofiltration; ECMO = extracorporeal membrane oxygenation; ED = emergency department; ICU = intensive care unit; LOS = length of stay; LVAD = left ventricular assist device; SD = standard deviation; UTI = urinary tract infection; VA = veno-arterial; VV = veno-venous.

a Reflects characteristics of 16 survivors with a total of 17 ECMO runs/hospitalisations.
b Reasons for disabled status: LVAD in place, anticipating heart transplant (n = 1); chronic fatigue and weakness (n = 1); chronic fatigue and severe migraines (n = 1).
c Underlying cause of respiratory failure was acute respiratory distress syndrome, secondary to pneumonia and/or empyema.
d Underlying causes of cardiogenic shock were ischaemic cardiomyopathy, nonischaemic cardiomyopathy, massive saddle pulmonary embolism, and postcardiotomy shock.

3.2. Contextual factors preceding the ECMO experience

As indicated by the FMSF, important contextual influences shaped the ways in which survivors viewed and described their illnesses and recoveries. The types and sizes of social networks, family makeup, previous experience with the healthcare system, and resources (within individuals and families) varied considerably (Fig. 1).

Figure 1. Diagram of ECMO survivor experience. ECMO = extracorporeal membrane oxygenation.

3.3. Themes

Survivors progressed through three phases: Trauma and Vulnerability, Resiliency and Recovery, and Survivorship (Fig. 1). Although survivors advanced from one stage to the next in successive order, progress was not consistently unidirectional, and recovery took differing amounts of time. Stages overlapped, and survivors described a multitude of factors that influenced how the illness affected their lives. Interwoven with the survivor experience were their interactions with healthcare providers and support received from their families. Illustrative quotations for stages and themes are provided in Table 2.
<table>
<thead>
<tr>
<th>Stage and theme</th>
<th>Subtheme</th>
<th>Exemplar quotation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1: Trauma &amp; Vulnerability</td>
<td>ECMO and the ICU</td>
<td>“I went upstairs to the cath [lab]. I remember them putting the stents in and I remember someone saying, ‘Get the paddles!’ And it was lights out.” [105P] “And not being sedated when you’re on ECMO, I know it’s unusual. I knew it was unusual when I did it but I also thought, look, if I’m willing to do that, I think the staff is going to say, you know, wow, look what this [person]’s willing to do. We’re going to fight as much as [he] is to save [his] life.” [207P]</td>
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<td></td>
<td>Being out of it</td>
<td>“It’s like a dream inside the dream inside the dream. Like that movie, Inception. It’s like you start to lose your mind. It’s like, I don’t know what’s real anymore.” [203P] “But when I woke up, honest to God, I mean, I thought it was, I said this can’t be real. I looked around and, you know, I couldn’t move. I couldn’t do this with my hand. I said how come I can’t lift my fingers? That’s the first thing I asked. Why can’t I lift my fingers or my feet? I couldn’t do nothing. And then I saw all these machines around me, right? Now I got a million IVs and everything else around me. I didn’t know where I was.” [206P] “I looked down and my stomach … I had an almost-healed suture all the way up my gut … I couldn’t say anything, but in my head, I was like oh my god, how long have I been out?” [203P] “They brought me to the ICU and I knew I was going to die. That was on the 19th of March. And then I remember [my husband] walked into my room, grabbed my hand, and he was crying. And I’m like, what the heck, he never cries. I’m like what are you doing, why are you crying? And he said do you know what day it is? And I’m thinking, oh, it’s March, you know. And he told me it was April 5th. And I remember being just blown out of the water. I had no idea.” [100P]</td>
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<td></td>
<td>Lack of control/Emotional responses</td>
<td>“I had the [breathing] tube down [my throat] so I couldn’t really communicate... I was focused on, ‘I wish I could get them to understand’... So, you’re conscious and people are communicating with you but you obviously can’t communicate back. That was the worst part for me.” [101P]</td>
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<td></td>
<td>Physical distress</td>
<td>“I had a million tubes in me, you know. Just tubes everywhere and everything.” [206P] “If [the breathing tube] moved, I really felt, literally like I was drowning in the saliva.” [101P]</td>
</tr>
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<td></td>
<td>Sleep and ICU routines</td>
<td>“It’s impossible to sleep in a hospital.” [200P] “I remember just the procedure every day. They would switch the nurses at 7 o’clock. The chest x-rays would be at 5am. To me, that’s what made sense. Like, things in a structure kind of thing.” [101P]</td>
</tr>
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</table>
| Stage 2: Resiliency & Recovery | From ICU to stepdown unit | “[In the ICU], it was like being in a cocoon, emotionally, and yes I was almost afraid to go the next step down.” [105P] “I remember ... when people said ‘stepdown,’ I thought, what is
<table>
<thead>
<tr>
<th>Finding a new normal</th>
<th>“And so, to me it was like, okay, I had this life before and now I had to kind of figure out this new life that I had to deal with.” [101P]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miracle</td>
<td>“[ECMO surgeon] came in and he just started crying and hugging me ... and he said, ‘I don’t usually meet people that are on that afterwards ... you had less than a 5% chance [of survival]’ ... He was just a stern doctor and to cry and hug me, it was just weird.” [100P]</td>
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<td></td>
<td>“They recounted to me how it was very touch and go ... the medical staff went to extraordinary lengths to revive me. Apparently, I was given 50 shocks ... they were at the point of giving up when I was revived.” [201P]</td>
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<tr>
<td>Learning to walk again</td>
<td>“When they got me up and moving, I had no muscles left in my legs ... my muscles disintegrated, weakened. They had to train me how to walk again. Once they got me up, I was determined to keep moving.” [208P]</td>
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<td></td>
<td>“The first time I got a shower I never realized how weak somebody could be. It feels like if you took a balloon and let all the air out and that was just enough to keep its shape, that’s what I felt. I had no energy, no strength or anything.” [202P]</td>
</tr>
<tr>
<td>Physical challenges</td>
<td>“A dozen times at least they had this [feeding tube] in me and they’d pull it out [when it became clogged]. It doesn’t hurt, but when they put that back in, you’d gag. I mean brutal.” [210P]</td>
</tr>
<tr>
<td>Stage 3: Survivorship</td>
<td>“But now it’s [the LVAD] second nature. It’s like putting your socks on.” (26 months post-discharge) [107P]</td>
</tr>
<tr>
<td>Psychological and cognitive difficulties</td>
<td>“And they’re like, oh, you should be over it by now, it’s been 5 years. But it doesn’t go away. It’s never going to go away. It’s part of my life. You know, every time I look in the mirror and see my nice 16-inch scar, it’s never going to go away. You think about it all the time and things set you off and you think of things ... It just seems like if I didn’t get sick or I didn’t make it, things would be better, because I wouldn’t have had to put anyone through that ... I felt for a long time that I was a disappointment because I did survive.” (60 months post-discharge) [100P]</td>
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<td></td>
<td>“My aunt is like, you don’t have PTSD, it’s only for army men. But I have the not sleeping, and the anxiety and triggers. I hear certain things and it will set me off and it will send me back.” (60 months post-discharge) [100P]</td>
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<td></td>
<td>“I know it’s different, I’m different. I know I am. And people don’t always see it, but I feel it and I see it in myself.” (e.g., difficulty with concentration and “losing words”) (43 months post-discharge) [112P]</td>
</tr>
<tr>
<td>Physical difficulties</td>
<td>“When you’re home, when you’re struggling to conquer your own house, getting up to the bathroom and barely be able to get out of a chair ... That’s really when it sinks in, you’re saying oh, man, I can’t do this?” (80 months post-discharge) [202P]</td>
</tr>
<tr>
<td>Section</td>
<td>Quote</td>
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<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>Life goes on</td>
<td>“To quote Donovan, the folk singer from the ‘60s, ‘what done been done.’ ‘I constantly stay moving forward.’”</td>
</tr>
<tr>
<td></td>
<td>“This upsets my family, but I kinda wish [my ECMO surgeon] didn’t save me sometimes.”</td>
</tr>
<tr>
<td></td>
<td>“After I came home from the hospital and people came to visit me, I would go into all of this excruciating detail that I’m recounting now to you. But that was for a short period of time. And then I realized that people really don’t want to hear about somebody else’s problems.”</td>
</tr>
<tr>
<td>Putting the pieces together</td>
<td>“When I was able to finally get in a wheelchair, even better, when I was able to walk, I went down to the ICU ⋯ I never met them because I was in a coma the whole time I was in there. The whole place broke down. The entire place started crying. And I couldn’t understand why until my wife told me, you know ⋯ I didn’t know what the hell happened.”</td>
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<td></td>
<td>“In the beginning I didn't need to know what happened to me. I needed to focus on recovery. But then I got to a point after the transplant when I got curious. I went on the internet and learned what my operation was and went, ‘oh, my god.’”</td>
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<td></td>
<td>“When I now go back and look at those pictures, it’s really kind of brutal. For my family, they saw those pictures along the way. In the moment, they lived those, they really did. And I didn’t. And now I go back and look at them, I’m like, wow, that’s hard to look at. I didn’t feel myself the way those pictures captured me ⋯”</td>
</tr>
<tr>
<td>Finding meaning</td>
<td>“Nothing that could happen to me going forward could be worse than what has happened to me in the past. And so, it gives you a confidence to overcome and to drive forward.”</td>
</tr>
<tr>
<td></td>
<td>“I’m a survivor because I can hug my grandchildren, I can love my wife, I can golf with my friends, I can drive a car, I can go on vacation. A survivor is being lucky that you can still live. It’s just telling my story to you.”</td>
</tr>
<tr>
<td>Family Support</td>
<td><strong>Physical presence</strong></td>
</tr>
<tr>
<td></td>
<td>“When I first woke up, I found out my mom was working every day, getting out of work, driving an hour from [work] up to [hospital] to see me and then leaving to go to work in the morning. She was with me every day.”</td>
</tr>
<tr>
<td>Family roles and advocacy</td>
<td>“And I wouldn’t have been able to do it without her. I don’t know how anybody that doesn’t have a family or somebody who are with them can go through this ... you can’t do it alone.”</td>
</tr>
</tbody>
</table>
“It wasn't a warm fuzzy homecoming. It was very uncomfortable. My family painted and cleaned the house while I was in the hospital. Things were thrown out, moved around, changed. And it just felt like it wasn't my house. I know they were just trying to help, but I felt violated.” [100P]

<table>
<thead>
<tr>
<th>Interactions with Healthcare Providers</th>
<th>Things to improve</th>
<th>“At one point my doctor, who was very nice – but it was very obvious he was waiting to go to the next person – said, ‘oh, you had a stroke,’ and left. I spent the afternoon crying. I thought my face had drooped. I thought I had had a massive stroke ... They would come in and make these announcements and then they would leave. And I just didn’t understand it.” [112P]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Things done well</td>
<td></td>
<td>“Their care was incredible, [doctors], nurses, everyone. As foggy as I was, they still were trying to keep me informed and tell me what was happening. But with my wife and son, they told them everything, they kept them informed all along.&quot; [107P] “The dedication that that team and that institution has to making sure their patients get the best possible care. I don't think that there is anyone who is just there for a paycheck, that these are people who are here because they believe in the mission.” [200P]</td>
</tr>
<tr>
<td>Patient suggestions to improve care</td>
<td></td>
<td>“[While I was in the hospital], I wasn’t at that point where I was asking questions yet ... And no one ever followed up, because I couldn't ask them to follow up.” [112P] “I was hoping to have a fellow survivor to just be able to sit down and talk. Just to say, did this happen to you, did that happen to you?” [100P]</td>
</tr>
</tbody>
</table>

ECMO = extracorporeal membrane oxygenation.

3.4. Stage 1: Trauma and Vulnerability

This first stage began at the time of onset of the ECMO-related illness and lasted (approximately) through the ICU stay. Trauma was manifested both physically and psychologically.

ECMO and the ICU – “I knew I was in for the fight of my life” [207P]

Many survivors lost consciousness before their arrival at the hospital, and most remained unconscious during the first days or weeks of their stays in the ICU. Almost all survivors were sedated while on ECMO and did not participate in the decisions to proceed with ECMO, nor remember its initiation. Most did not remember anything during the ECMO period aside from scant, fuzzy memories.

One person was conscious during most of his time on ECMO. He was advised to reconsider his decision to remain awake and was told that his experience in the ICU (if he remained conscious) would be “horrific.” [207P]. However, he felt strongly that fighting to stay alive was synonymous with maintaining as much normalcy as possible and thus advocated to remain awake on ECMO. For a brief period on the day of his cannulation, he second-guessed this decision and felt bombarded by an array of unfamiliar sights, sounds, and sensations: “It was tough, you know, to see all your blood coming out of your body.” Although limited in his ability to move, he continued to do work via his phone and tablet computer. Despite a complicated ICU stay, he reported no negative long-term psychological sequelae and had no regrets about his decision to remain awake. He remained convinced that when healthcare providers could see him actively fighting for his life, they were more likely to fight harder on his behalf.
**Being out of it** – “It’s like a dream inside the dream inside the dream” [203P]

Most survivors recalled having vivid “coma dreams” or hallucinations that ranged from serene and comforting to bizarre and gruesome. Some began to awaken before objective signs of gaining consciousness were observed by others. Almost every survivor described hazily emerging from sedation (e.g., “foggy”; “out of it”). Most had no idea where they were or why they might be in the ICU. Time was difficult to gauge, and many survivors did not know how much time elapsed between their presentation to the ICU and awakening.

**Lack of control/Emotional responses** – “I wish I could get them to understand” [101P]

In the ICU, survivors most commonly experienced anxiety soon after emerging from sedation, especially if they were still intubated. The survivor who remained awake while on ECMO recalled having particularly benefited from regular conversations with a psychiatrist. Deficiencies in communication, knowledge, and comprehension were common sources of frustration, as they limited survivors’ ability to advocate for themselves regarding their health status. Three survivors described significant feelings of loneliness, especially at night.

**Physical distress** – “A million tubes in me” [206P]

Survivors frequently mentioned the insertion, ubiquitous presence, and removal of lines, tubes, wires, IVs, and drains. Most people remembered the presence of a “tube down my throat” and described sensations of drowning in saliva, gagging, and suctioning that felt like “taking [your] breath away.” Survivors universally experienced pain or discomfort, usually related to surgeries and procedures or associated with the presence of invasive lines and tubes (especially endotracheal, nasogastric, and rectal tubes). For two people, feeling pain was reassuring. “I'll deal with the pain. Pain lets you know you're alive.” [100P]

Movement was arduous, as every survivor described profound generalised weakness and fatigue. “I couldn't hold my head straight”; “I couldn’t even find my mouth with a plastic spoon when I first came around from the sedation.” [201P] While intubated, participants had varying success with communicating by mouthing words; all were too weak to write.

**Sleep and ICU routines** – “The procedure every day ... that's what made sense” [101P]

Many survivors described difficulties with sleep while hospitalised. Survivors gained confidence in foreign and often unpredictable ICU environments by recognising patterns, especially in healthcare provider behaviours and routine tests. It was helpful for several survivors to have daily schedules and anticipate activities updated on the white board in their room.

3.5. Stage 2: Resiliency and Recovery

The second stage represented (approximately) the time from transition out of the ICU to the return home. However, aspects of the recovery process extended past the period of hospitalisation; for some survivors, healing was still incomplete, even years after the illness.

**From ICU to stepdown unit** – “It was like being in a cocoon” [105P]

Most survivors remembered their transfer from the ICU to the stepdown unit. Many were apprehensive about leaving the “safety” of the ICU, particularly if they had LVADs, but others were eager for this transition. One person contrasted his experience in the stepdown unit as “heaven” compared with his negative experience in the ICU.

In the new setting, survivors eventually learned about details from the ECMO period from family members or healthcare providers. Only two survivors had any familiarity with ECMO before their illness. Nine survivors of VA ECMO had LVADs implanted, intended as bridges to transplantation.
Finding a new normal – “I had to figure out this new life” [101P]

Symptoms of delirium persisted for some people who described an inability to think clearly or logically. Survivors grappled with the potential implications of their illnesses for the first time and tried to imagine what their futures might be. After weeks or months of strenuous recovery efforts, many survivors found themselves temporarily overcome by their frustrating, exhausting, and slow progress (e.g., “It was just one thing after another;” “I just didn’t want to do it anymore”) [206P]. Often, their drive to forge ahead was restored after having forward-looking, constructive conversations with loved ones or healthcare providers.

Miracle – “They told me, ‘my god, you survived that? Congratulations!’” [105P]

Healthcare providers acknowledged the remarkability of survivors’ recoveries and often celebrated survivors as “miracles” who were “very lucky” to be alive. For survivors, especially without more details about their hospitalisations and clinical courses, the concept of having almost died was abstract. They described this phenomenon as “weird” or “strange,” as though the principal characters in the story were the last ones to discover the plot. For some, the concept of being seen as a “miracle” felt oppressive or burdensome.

Learning to walk again – “I never realized how weak somebody could be” [202P]

With strenuous effort, survivors detailed a gruelling progression from prolonged bedrest to being liberated from the bed and eventually to independent ambulation. Speed and quality of physical recovery were often described as faster for younger survivors and slower for those with preexisting orthopaedic problems or severe illness-related complications. Most survivors required short-term (usually 1 month or less) stays at rehabilitation facilities before they returned home.

Physical challenges – “I went from 210 pounds to 150 pounds” [206P]

One survivor remained ventilator-dependent throughout the hospitalisation and for most of a 2-month stay at a long-term care rehabilitation facility. Two survivors regained their voices after treatment for vocal cord paralysis and use of a tracheostomy speaking valve. Several people had persistent difficulty with swallowing. Many survivors reported considerable weight loss, ranging from 35 to 60 pounds, during their hospitalisations. Pain and difficulties with sleep persisted for many survivors throughout their hospitalisation.

3.6. Stage 3: Survivorship

This third stage extended (approximately) from the time survivors returned home until the time of the interview (range: 11–90 months).

Adapting to ECMO survivorship – “It kinda hits you when you're home ... I was really sick” [202P]

Most survivors were eager to learn more about ECMO from healthcare providers, family members, and online searches. Several people wondered whether treatment with ECMO was related to some of their self-reported long-term cognitive and physical difficulties. They understood the severity of their illnesses, how close to death they came, and described ECMO as a sort of “Hail Mary” attempt to save them. At the time of the interviews, two survivors were still living with LVADs. Initially they depended heavily on assistance from family members, but eventually they became comfortable with aspects of LVAD care. Survivors slowly resumed responsibilities and hobbies and reestablished family roles and activities. Just over half returned to work, but others transitioned into retirement or life with permanent disability.

Psychological and cognitive difficulties – “You think about it all the time” [100P]

Two-thirds of survivors struggled with at least one psychological or cognitive difficulty. The most common involved symptoms of chronic depression or discouragement (“I can’t do what I used to do.”). All three people
who experienced loneliness during their hospitalisation continued to experience loneliness years after their illness. Social isolation was exacerbated by functional limitations, logistical complications, and changes in family roles and function. One person enumerated significant symptoms of posttraumatic stress: flashbacks to the ICU, avoiding returning to the hospital, difficulty sleeping, and negative feelings (e.g., anxiety, depression, fear, guilt).

Many survivors reflected about time “lost” to them between losing consciousness before ECMO treatment and emerging from sedation. For three people, “losing” these days or weeks felt particularly unsettling and was illustrative of their powerlessness during that period. Concentration difficulties for a few survivors made much-loved pastimes more challenging. They recounted how they now often “lose words” or have difficulty “pulling up words.” One person described severe short-term memory loss, difficulty planning even routine activities, hyperactivity, and loss of inhibition in the years after her illness.

Physical difficulties – “My legs are just like spaghetti sometimes” [112P]

Once discharged home, almost all survivors continued to receive care from home-care nurses, physical therapists, and/or cardiac rehabilitation programs. Difficulties with weakness and fatigue affected most people for weeks and months after hospitalisation. Some survivors were still affected by these symptoms, years after their illnesses. At the time of interview, most had returned to their previous level of function, some continued to suffer from chronic health problems, and a few had exceeded their preillness state of physical fitness.

Survivors with chronic physical symptoms described upper and lower extremity joint pain, arm numbness, severe migraines, severe vertigo, neuropathic pain, and a sensation of always feeling cold. A small subgroup of these survivors continued to have sleep problems that persisted years after their illnesses and overlapped with symptoms of moderate to severe anxiety and depression.

Life goes on – “ECMO gave us a whole new life” [206P]

The illness requiring ECMO imposed drastic changes to survivors' lives and often created a stark contrast between their pre-ECMO and post-ECMO selves, including changes in self-perception, roles, abilities, restrictions, and relationships. The incongruity between current existence and the life they used to have (“this isn't my life, that's my life”) served both as major sources of motivation (to regain normalcy) and depression and frustration (if their efforts to reestablish normal life fell short). Survivors attempted to adjust by developing new or additional coping mechanisms (e.g., exercise and mindfulness practices, humour, goal-setting), reimagining their futures, and/or reconciling the realities of postillness life. Two survivors expressed ambivalence, questioning whether it might have been better if they had not survived. Several survivors mentioned that they rarely discussed their illness with others because almost no one they knew could relate to the complexities of this experience.

Putting the pieces together – “It takes a little while to understand what happened” [203P]

Having been unconscious or otherwise unaware of their health condition for days or weeks, most survivors wanted to “fill in the gaps” by piecing together their own memories with facts provided by healthcare providers and/or family members. In this way, they could begin to reclaim ownership of their experiences and feel prepared to “move on” with their lives. Deficits in this knowledge contributed to a sense of diminished self-efficacy and increased isolation. Most survivors mentioned notes, pictures, or videos taken by family during their illness. Their feelings about this documentation varied from “validating” to “see the difference” over the course of recovery to “brutal” or “depressing” to view.

Particularly important for participants with significant long-term sequelae was lack of access to adequate, personalised follow-up care. By the time that survivors identified or had the capacity to communicate potential causes for concern, they had been discharged from the hospital. Without obvious mechanisms to communicate
with members of the ECMO team, many survivors were left with important questions about their current functional deficits. They sometimes turned to healthcare providers they had ready access to, usually primary care providers. However, these clinicians were typically unaware of the details of the ECMO clinical course and unable to provide answers to specific questions or about lingering symptoms.

**Finding meaning** – “A second chance at life” [205P]

Each survivor, to varying degrees, sought to find meaning in their experiences. Some invoked religious or spiritual interpretations, while others expressed gratitude for the science that produced this lifesaving technology. Most returned to the firehouses and/or hospitals where they had received care to express their appreciation to emergency medical personnel and healthcare providers. About one-third of survivors endeavoured to “pay it forward” by engaging in volunteer work or fundraising efforts at their ECMO institutions.

People had different ideas of what it meant to be “a survivor.” Many felt they had a more balanced perspective about their lives. Others considered their illness experiences as a “wake-up call” that inspired changes in life priorities. Some felt emboldened, believing that few future life challenges could rival what they already survived.

### 3.7. Family support

Each survivor had a primary support person or a small core group who played critical roles in their stories, from the onset of illness through long-term survivorship. The support – or lack thereof – of these family members and friends played a major influence on the course of survivors’ short- and long-term outcomes.

**Physical presence** – “My family was there 24/7 for me” [101P]

In most cases, family members maintained a steady physical presence while survivors were hospitalised, which translated into less loneliness, increased peace of mind, and more effective advocacy on behalf of survivors. A few family members were unable to visit survivors regularly, usually for logistical reasons. In rare cases, family members could have been present but decided against it, ostensibly because they felt overwhelmed or underestimated either the severity of illness or the value the survivor placed on their presence.

**Family roles and advocacy** – “You can’t do it alone” [107P]

Survivors eventually discovered the extent to which many of their family members put their own lives “on hold” to support the survivor, and, frequently, the family group. Family members made life-and-death decisions during the period of critical illness and “took shifts” at the hospital, so they would not miss morning rounds or opportunities to learn updates from healthcare providers.

Survivors depended on their families for physical, emotional, and logistical needs throughout their recoveries. Occasionally, survivors felt that their family members could have, or should have, advocated more forcefully on their behalf. On rare occasions, survivors interpreted behaviours of family members as manipulative or “violating.”

### 3.8. Interactions with healthcare providers

Survivors’ interactions with healthcare providers were highly influential, particularly in the earlier periods of illness. In this time of great uncertainty, the messages survivors heard from healthcare providers were critically important, not only for accurate understanding of their own current states of health but also in setting expectations for the future.

**Things to improve** – “I never got the full story” [112P]

One person who was ventilator-dependent for her entire hospitalisation recalled numerous instances when physicians would “pop in” and talk to her but did not allow time for her to ask questions or seek clarification,
which left her feeling confused and frustrated. Two survivors recalled what they perceived as rude or unprofessional behaviour by healthcare providers. Limited access to physical therapy during their stays in rehabilitation centres was a source of frustration for several people.

**Things done well – “Their care was incredible” [107P]**

With few exceptions, survivors expressed profound gratitude for the lifesaving care they received. They felt cared for and encouraged by an extensive network of healthcare providers and staff. Most participants reflected on the extraordinary nature of their relationship with members of the ECMO team. Trusting relationships were established with the provision of excellent care and when healthcare providers communicated information that was consistent and clear, in a manner that was compassionate and appropriate in both tone and timing. This required accurately gauging what was necessary in those moments and “meeting people where they were at,” providing enough information to empower but not so much that would overwhelm.

3.9. Patient suggestions to improve care

Regardless of survivors’ illness and recovery experiences, they universally endorsed several interventions: (i) early identification and treatment of survivors with mental, emotional, cognitive, and/or physical health problems; (ii) assistance from healthcare providers to access local treatment resources (e.g., mental health counselling services); (iii) opportunities to ask questions to healthcare providers knowledgeable of their hospital courses, fill in memory gaps, and establish realistic expectations for the future; and (iv) to talk with others who have gone through similar experiences.

4. Discussion

Adult survivors of ECMO-related illnesses progressed through three stages (Trauma and Vulnerability, Resiliency and Recovery, and Survivorship) with mixed experiences and outcomes. Their illness experiences were deeply influenced by their specific contexts, support from family, and interactions with healthcare providers. Our model (Fig. 1) captures the interplay of these dynamics over the trajectory of the illness and recovery experiences.

The issue of survivorship after critical illness is a growing topic of interest for clinicians and researchers. Functional disabilities that exist for these survivors may include symptoms of anxiety, depression, and posttraumatic stress; problems with executive function, memory, and attention; and difficulties in physical function. This triad of psychiatric, cognitive, and physical impairments that arise in the ICU but persist after hospital discharge is called post–intensive care syndrome (PICS). Although long-term outcomes of ICU survivors (not treated with ECMO) have been explored extensively and those of patients treated with ECMO more recently, the prevalence of PICS among ECMO survivors appears to mirror those of other critical illness populations.10 Our findings are largely consistent with those described in previous studies.

Results from recent systematic reviews and meta-analyses show that in the first year of hospital discharge after critical illness (without ECMO), about one-third of ICU survivors will experience symptoms of anxiety,32 one-third depression,33 and one-fifth posttraumatic stress disorder (PTSD).34 Individual studies of ECMO survivors have reported symptoms of anxiety in up to half of patients, depression in almost one-third, and between 5 and 41% at high risk for developing PTSD.10 Prevalence of cognitive impairment for ICU survivors varies widely, depending on the type of assessments used and aetiology of critical illness.35 Data on neurocognitive outcomes after treatment with ECMO are limited and results vary widely, with deficits reported in 9–43% of patients.36,37 The most common physical problem, ICU-acquired weakness, affects more than 25% of ICU survivors;31 in our sample, weakness and fatigue were ubiquitous and profound.

One year after hospital discharge, only about 60% of ICU survivors return to work.38 Among those that return, as many as one-third suffer job loss, up to two-thirds change occupations, and up to 83% experience diminished
employment (such as fewer hours worked). Though a majority of ECMO survivors return to work within 1 y of hospital discharge, as few as one-quarter may be able to resume their previous work. In our sample, 25% of participants were never able to return to work after their illnesses.

Although significant parallels exist, some aspects of the ECMO experience may be distinct from responses to other critical illnesses and treatments. For example, the ECMO circuit and cannulas present challenges not necessarily experienced with other patient populations (e.g., increased risk of infection, bleeding, lower limb ischaemia; barriers to physical mobility). In addition, as noted by our participants and elsewhere, most survivors of ECMO-related illnesses experience difficulties such as profound weakness/fatigue, extensive weight loss, and high potential for disability (Table 3).

Table 3. Experience of ECMO and other critical illnesses: similarities and differences.

<table>
<thead>
<tr>
<th>Experiences shared with other survivors of critical illness</th>
<th>Experiences distinct with treatment with ECMO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period of critical illness</td>
<td>- Nature of illness onset</td>
</tr>
<tr>
<td>- Incomplete or non-factual memories of critical care period</td>
<td>- Rapid health deterioration and crisis</td>
</tr>
<tr>
<td>- Altered perceptions of reality and time</td>
<td>- Severity of illness</td>
</tr>
<tr>
<td>- Challenges during transition from the ICU</td>
<td>- Lengthy ICU and hospital LOS</td>
</tr>
<tr>
<td>- Care, communication, and relationships with healthcare providers</td>
<td>- Prolonged exposure to difficult and traumatic experiences</td>
</tr>
<tr>
<td>- Dependency on medical technologies</td>
<td>- Specific challenges related to the ECMO circuit and cannulas</td>
</tr>
<tr>
<td>- Desire for human contact</td>
<td>- Higher risk of infection</td>
</tr>
<tr>
<td>- Difficulties in the critical care environment (e.g., helplessness, frustration, difficulty communicating)</td>
<td>- Platelet dysfunction and coagulopathy, systemic heparinisation, bleeding</td>
</tr>
<tr>
<td>- Support of family and friends</td>
<td>- Cannula-specific complications (e.g., pain, delayed wound healing, neurovascular problems, lower limb ischaemia)</td>
</tr>
<tr>
<td></td>
<td>- Unique challenges to early mobilisation (e.g., profound neuromuscular weakness, maintaining integrity of ECMO cannulation sites and circuit, considerations for haemodynamic and pulmonary status while ambulating)</td>
</tr>
</tbody>
</table>
Recovery and survivorship
- Cognitive deficits (e.g., attention, short-term memory)
- Physical health challenges (e.g., pain, mobility, fatigue, weakness, sleep disturbance, sensory changes)
- Presence of new disability or functional limitations (e.g., mobility challenges, difficulty with independence in ADL)
- Mental health challenges (e.g., anxiety, depression, PTSD, irritability, anger, frustration, mood changes, inability to successfully cope with stress, loss of motivation)
- Negative emotions (e.g., boredom, loneliness/isolation, wish they had not survived)
- Positive emotions (e.g., new sources of motivation, acceptance, gratitude)
- Challenged to develop effective coping mechanisms (e.g., optimism, hope, support of friends and family, spirituality, self-sufficiency, sense of humour, readjusting expectations for future)
- Challenged to reconcile preillness and postillness realities; attempt to “move on”
- Challenged to resume social roles and activities (e.g., return to hobbies, return to work)
- Changes in relationships with family and friends (e.g., social dynamics, social connectedness, intimacy, relationship strain)
- Belief that others cannot or do not understand transformational nature of critical illness experience

Desire to find/restore meaning to lives

Note: ADL = activity of daily living; ECMO = extracorporeal membrane oxygenation; ICU = intensive care unit; LOS = length of stay; PTSD = posttraumatic stress disorder.

Our study revealed new findings. First, in contrast to other qualitative investigations of the experience of ECMO, our participants frequently discussed issues related to LVADs (all but two survivors had heart failure/cardiogenic shock). The challenges of living with LVADs are not unique to ECMO patients but nonetheless were described as an important part in the overall recovery experience of many participants. Second, most of our participants distinctly remembered how some of their healthcare providers reacted to their clinical progress and survival. These reactions of amazement left a lasting imprint and were important in two ways. They were often survivors’ first indicators that their illnesses were exceptionally severe. Later, those reactions served as validation; survivors remembered how sick they had once been, and with that perspective, their lengthy and difficult recoveries were more understandable.
4.1. Clinical relevance and implications

Because of improved survival rates, shifts in clinical management of adult ECMO patients\textsuperscript{44} and the tremendous resources devoted to their care,\textsuperscript{45} it is crucial to consider implications for survivorship even from the earliest days in the ICU.\textsuperscript{46} For the survivors in this study, experiences and needs varied. For some participants, the period of ECMO treatment represented the peak of uncertainty and most difficult experiences during their critical illness. For others, ECMO treatment was only the first hurdle to clear, as they went on to face other prolonged and complex health challenges. Persistent difficulties with aspects of physical and mental health were common, yet frequently inadequately addressed by the healthcare team. Participants in our study sought to fill in memory gaps resulting from periods of coma, delirium, and/or communication difficulties.\textsuperscript{47} They also wished for more opportunities to share their illness experiences with others who could understand what they have been through. Data from existing literature and participants in this study suggest that to meet the multitude of needs in this population, numerous aspects of post-ICU care should be considered (Table 4).\textsuperscript{12,47,48,49,50}

Table 4. Post-ICU follow-up care for adult ECMO patients.

<table>
<thead>
<tr>
<th>Recommended aspects of care</th>
</tr>
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<tbody>
<tr>
<td>1. Screen early for mental, physical, cognitive, functional, and social health problems with referral to support services as needed</td>
</tr>
<tr>
<td>2. Allow opportunities for survivors to ask questions and provide information to fill in memory gaps</td>
</tr>
<tr>
<td>3. Guide survivors to establish realistic expectations for the future and acknowledge uncertainties</td>
</tr>
<tr>
<td>4. Cultivate survivors’ adaptive coping skills (e.g., build resiliency, improve emotional awareness, stress management)</td>
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<td>5. Provide additional patient education as needed</td>
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<tr>
<td>6. Connect survivors to relevant resources in their own communities</td>
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<tr>
<td>7. Mobilise survivors’ social resources</td>
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<tr>
<td>8. Consider peer support/peer debriefing opportunities</td>
</tr>
<tr>
<td>9. Multidisciplinary, collaborative team approach</td>
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<tr>
<td>10. Evaluate long-term outcomes</td>
</tr>
</tbody>
</table>

ECMO = extracorporeal membrane oxygenation; ICU = intensive care unit.

4.2. Recommendations for future research

Our findings highlight areas for future study. Although patients are often deeply sedated and immobile during the period of ECMO treatment,\textsuperscript{51} clinical strategies to reduce sedation and immobility are increasingly common;\textsuperscript{52,53,54} more research is needed to evaluate long-term outcomes for patients who are awake and/or mobile during ECMO treatment. Systematic evaluation of outcomes is needed and will improve understanding of ECMO survivors’ experiences and needs.\textsuperscript{10,12,55} Future investigations should evaluate the development and effectiveness of interventions that improve long-term outcomes in this population.\textsuperscript{10,12,56,57}

5. Strengths and limitations

To our knowledge, our study is the first to explore the experiences of adult ECMO survivors from the time of ECMO-related illness onset through late recovery. We incorporated multiple sources of data and integrated a broad array of perspectives from our sample of survivors. All participants were long-term survivors, and we benefited from them having spent considerable time reflecting on various aspects of their experiences and their ability to share those deep insights through comprehensive interviews. Our sample included participants treated between 11 months and 7.5 years before study enrolment, which added a diversity of perspectives but may have contributed to recall bias as memories can shift and fade with time.\textsuperscript{58} Furthermore, the goal of this study
was to understand the contextual and individual meanings of these experiences, and not merely to solicit factually accurate situational recall. Participants were treated with ECMO between 2010 and 2017; it is possible that over that period, changes in clinical practice or ECMO program policies could have influenced survivor experiences and overall outcomes. Most participants identified as male, and all were white and non-Hispanic; this is largely representative of the overall population treated with ECMO. 58 Most tended to be fairly healthy before their ECMO illnesses, which may limit transferability of our findings. We used different recruitment strategies at each site, which increases risk for potential selection bias. Overall response rate was 33%; response rates were higher when potential participants were invited directly by the clinical site coordinator than by recruitment letter alone. Given respect for patient confidentiality, we relied on site coordinators to identify and invite participants and we did not have access to clinical or demographic characteristics for patients unless they consented to be involved in the study. Thus, we cannot determine who chose not to participate or why. It is possible that some survivors did not receive the invitation letters or were reluctant to participate for any number of reasons. The risk for survival bias increases if those with poorer long-term outcomes were less likely to participate in this study. Despite careful interviewing about these survivors’ experiences, it is challenging to separate the effects of ECMO from the consequences of critical illness more generally.

6. Conclusions
The ECMO experience was life-altering, and survivors faced long and difficult recoveries. The successful merging of aspects of their “old” lives with new challenges posed in the wake of life-threatening illness demanded considerable resources and compelled survivors to adapt. Recoveries were bolstered by the support and advocacy of family and friends. Development of trusting relationships with healthcare providers was crucial for optimising short- and long-term outcomes. Survivors would likely benefit from predischarge screening to identify mental, physical, or functional health problems, opportunities for peer support, and comprehensive post-ICU follow-up health services.

Funding
Research reported in this publication was supported by the Rockefeller University Heilbrunn Family Center for Research Nursing through the generosity of the Heilbrunn Family, the National Institute of Nursing Research (NINR), and the National Center for Advancing Translational Science (NCATS) of the National Institutes of Health under award numbers T32NR008346 and UL1 TR00184. Its contents are solely the responsibility of the authors and do not necessarily represent the official view of the NIH.

Conflict of Interest
None.

References


