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Care of Patients With Acute and Critical Illness

A qualitative exploration of acute care and psychological distress experiences of ECMO survivors

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ABSTRACT

Objectives: To explore the acute care experience of extracorporeal membrane oxygenation (ECMO) patients.
Background: ECMO is used in life-threatening scenarios of acute lung or heart failure. The patient's experience with ECMO treatment and the psychological distress are unknown.
Methods: Qualitative analysis of semi-structured interviews with ECMO survivors 12 months after discharge were conducted and thematically analyzed.
Results: Ten participants treated with ECMO for life-threatening acute heart or lung failure were interviewed. Six themes that captured the ICU experience of ECMO patients were identified including; dealing with crisis, critical care, memory, role of significant others and existence today and tomorrow. Deconditioning was the most frequently reported experience. Patchy factual memories contrasted with detailed delirious memories and paranoid ideations.
Conclusion: Patients treated with ECMO experienced deconditioning, perceived threats of serious injury or death and delusional episodes with recalls of psychological distress.

Introduction

Intensive Care Unit (ICU) survivors are at risk of a magnitude of long term physical, cognitive, and mental health impairments.[1–3] These new or worsening health problems following critical illness have been recently defined as post-intensive care syndrome (PICS).[2] PICS related physical impairments include critical illness neuropathy and ICU-acquired weakness, cachexia or wasting syndromes, which result in deconditioning and immobility.[4,5] PICS related cognitive impairments are persistent in many survivors and have been directly linked to the experience of acute brain dysfunctions (e.g. delirium) during ICU stay.[6,7] PICS related mental health impairments including anxiety, depression and post-traumatic stress disease (PTSD) negatively affect functional status and quality of life.[5,8]

PTSD, one possible PICS-related mental health impairment, is a stressor-related disorder and the essential features are characteristic symptoms that follow exposure to one or multiple traumatic events.[9] PTSD is diagnosed if exposure to actual or threatened serious injury or death is directly experienced or witnessed (gatekeeper criterion A) and causes the following symptoms: *Intrusion* (involuntary memories, distress to cues that symbolize the event, flashbacks); *Avoidance* (of distressing memories); *Negative cognition/mood* (inability to remember aspects of the event or negative emotions) and *Hyperarousal* (irritable behavior, sleep disturbance). Symptoms must last longer than one month and cause significant clinical distress or impairment in social, occupational or other important areas of functioning.[9]

Patients treated with extracorporeal membrane oxygenation (ECMO) are at risk to develop PICS and frequently report adverse

Abbreviations: ARDS, acute respiratory distress syndrome; ECMO, extracorporeal membrane oxygenation; HF, heart failure; ICU, Intensive Care Unit; IQR, interquartile range; LVAD, left ventricular assist device; LTx, lung transplantation; PTSD, post-traumatic stress disease; SD, standard deviation; VF, ventricular fibrillation; VSD, ventricle septum defect.

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health outcomes like PTSD after discharge.[10–13] PTSD symptom burden is as high as 41% in some long term survivors of ECMO treatments and this figure is double the prevalence found in general intensive care survivors.[14,15] ECMO is a rescue therapy for patients that are at great risk of dying from acute lung or heart failure.[16] In stable patients, ECMO is considered when the risk of dying is greater than 50% but it is also instigated in acute deteriorating or even dying patients (cardiac arrest).[17] During ECMO treatment in the ICU, the patient's blood is actively pumped through an artificial lung that is external to the body and provides gas exchange and blood pressure support for hours to weeks until the underlying condition has resolved.[17] Common conditions that lead to ECMO treatment include acute respiratory distress syndrome, cariogenic shock or primary graft dysfunction following transplant.[17]

Exposure to these life-threatening circumstances in which ECMO is instigated may cause high risk for PTSD in this patient group.[11,13,14] However, patients' experiences related to those life-threatening situations and ECMO treatment that may lead to high risk for PTSD are unknown. The purpose of this study was to qualitatively explore the acute care and psychological distress experiences of ECMO survivors.

Methods

This study was part of a prospective observational cohort study that investigated health-related quality of life and mental health of patients treated with ECMO in ICU 3, 6 and 12 month post discharge. Patients, 18 years or older, admitted to ICU and treated with ECMO from 2013 to 2014, and enrolled in the prospective observational cohort study were eligible for inclusion in this qualitative study. A convenience sampling strategy was applied.[18] All consecutive participants that completed the 12 month survey were invited to participate in the interviews. Participants were excluded if they did not speak English; had cognitive or neurological impairments that would preclude completion of interviews; or if they had terminal conditions. The prospective observational cohort study was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12614000337673) and was approved by the local ethical review committee.

Design and data collection

Qualitative semi-structured interviews with participants were conducted in person (six participants) or over the telephone (four) one year after ECMO treatment. Interviews were conducted until thematic saturation was reached.[19] The interviews covered a broad range of participant's perceptions and experiences along chronological stem questions as exemplified in Table 1. All interviews were conducted by the same facilitator (RT), audio recorded and externally transcribed by a professional transcribing service. Audio and transcripts were imported into NVivo 10, a qualitative software for data management and analysis preparation.[20] All transcripts were checked against the original audio files by one researcher (RT). Trustworthiness was established with the principles of credibility, dependability and confirmability.[18] RT has many years of clinical experience with ECMO and conducted all surveys, tests, follow-up calls and interviews as part of prolonged engagement and persistent observation strategies that established credibility.[21] Dependability was established with the reading and re-reading of the transcripts (RT, KM), independent development of themes by two researchers (RT, KM) and audit trails during full research team meetings. Confirmability was established with direct quotes within the results section.

Table 1
Sample interview questions.

Topic	Question
Introduction	Hello and Welcome [Name].Thank you for taking the time today to do this interview with me. More than 12 months ago you were in hospital and treated with ECMO. Today I am curious to hear about your perceptions and experience with ECMO treatment and everything else you find important …
Life and health before hospital admission	Please tell me how it all started. What happened before hospital admission? Were you sick before admission?
Admission to hospital	Do you remember what happened during hospital admission? Transfer from elsewhere? Problems? Last thing you remember?
ICU	Let's talk about ICU. You have been in ICU for XX days. What do you remember from ICU? What was it like to be an ICU patient? What was stressful/helpful during that time? How about relatives and visitors? Does the ICU experience still affect you?
…	…

Data analysis

The analysis was performed by way of a thematic analysis.[18] Thematic analysis allows to explore themes that are anticipated as well as those that emerge from the field work.[22] A six-step process was used to perform the thematic analysis, which included; (i) familiarization with the data by reading each transcript; (ii) generating initial codes; (iii) searching for themes from the initial codes; (iv) reviewing the themes by generating a 'thematic map'; (v) defining and naming themes; and (vi) producing the final analysis.[23] The generated thematic map relied on deductive approaches of anticipated themes from interview stem questions and inductive approaches where themes arose during the analysis.[22] Steps 1–5 were done independently by RT and KM and any differences in themes were resolved by discussion with the whole team during the final analysis.

Results

Ten ECMO survivors were interviewed 12–13 months post ECMO treatment. Three participants were female; most participants were admitted externally; spent a median (IQR) of 18 days (11.5–25.2) in ICU; were mechanically ventilated for a median (IQR) of 11 days (6.5–15); were for a median (IQR) of 5 days (3.25–6.75) on ECMO and were discharged home after a median (IQR) of 34 days (26.5–42.5). In person interviews tended to be longer than telephone interviews and lasted 72 min on average (42–117 min). Baseline characteristics and clinical data of participants are presented in Table 2.

Six main themes were identified in the qualitative exploration of ECMO survivors' experience of admission and ICU (*Crisis*, *Being in ICU*, *Good and Bad Experiences*, *ICU Memory*, *Significant Others* and *Existence Today and Tomorrow*).

The themes are summarized below and accompanied by exemplary in-text quotations from participants.

Crisis – dynamics in deterioration

Most participants were admitted from the Emergency department and transferred to ICU. Some were already in hospital for transplant surgery while others were retrieved from external ICUs. The underlying conditions that led to ECMO initiation varied and are depicted in Fig. 1.

Although time from onset to deterioration varied, most participants experienced a crisis due to rapid symptom deterioration and emergent use of ECMO treatment.