



Problems and health needs of adult extracorporeal membrane oxygenation patients following hospital discharge: A qualitative study



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ABSTRACT

Objectives: To explore problems and health needs of adult extracorporeal membrane oxygenation (ECMO) patients during a one-year period following hospital discharge.

Background: ECMO functions as life support during treatment of advanced cardiac and respiratory failure. Knowledge regarding the problems and health needs of discharged adult patients who have undergone ECMO is lacking.

Methods: This study used a qualitative descriptive interview design. Fourteen adult ECMO patients were recruited by purposive sampling prior to discharge. Data were generated from semi-structure in-depth interviews at 3-month intervals following hospital discharge.

Results: Four themes described problems and needs post-discharge: stress resulting from ECMO surgery; making health a priority; support from family friends and health care professionals; and emotional support.

Conclusions: Multidisciplinary evidence-based interventions should be implemented prior to or soon after discharge to help with the physical, psychological and social problems that ECMO survivors experience, which can help improve their quality of life.

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Introduction

Extracorporeal membrane oxygenation (ECMO) is a form of cardiopulmonary bypass that provides temporary cardiac and respiratory support during treatment and recovery for critically ill patients.¹ ECMO enables patients to remain stable during the waiting period for organ transplantation and provides additional time to evaluate a patient's status and determine appropriate treatment.^{2,3} Originally used for cardiovascular failure, ECMO is also initiated for myocarditis, unsuccessful weaning from cardiopulmonary bypass, acute lung failure, and acute respiratory distress syndrome (ARDS).² The Extracorporeal Life Support Registry Report 2012 reported that through 2011, the number of adults treated for

respiratory failure with ECMO was approximately 400 adults per year with a survival rate of 55%.⁴ In Taiwan the use of ECMO increased dramatically between 2000 and 2010.⁵ Reported survival rates have been reported to be 47.7% for adults with ARDS,⁶ 74% following weaning from ECMO,⁷ 34.8% at the time of hospital discharge,⁸ and 29% one year after hospital discharge.⁹

ECMO removes deoxygenated blood from a major vein accessed by percutaneous puncture, oxygenates it by gas exchange outside the body and returns it. There are two common ECMO approaches: venoarterial (VA) and venovenous (VV). VA ECMO provides hemodynamic support; venous blood is returned to the aorta (usually via the femoral artery) providing both respiratory and cardiac support. VV ECMO is used for respiratory failure not responding to mechanical ventilation; it provides pulmonary support and venous blood is returned directly into the right atrium.^{10,11} In this extracorporeal circuit system, the blood pump functions as a temporary heart, and the oxygenator functions as lungs. ECMO maintains

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circulating blood, which reduces hypoxia and reduces the burden on the heart or lungs.^{2,12}

The duration of ECMO support varies from one day to two weeks.^{9,11–15} During this period various problems can occur; acute renal failure, bleeding or infection at the cannula access sites, gas exchange impairment, alterations of cardiac output, ischemic necrosis of lower extremities, intracranial hemorrhage, poly-myopathy, and polyneuropathy.^{13,16–18} Patients are weaned from ECMO support as soon as possible, however lower limb paresthesia, lower limb ischemia, and increased psychological stress may occur after the withdrawal of ECMO.¹⁸ Physical health is impacted after hospital discharge; complications such as lymphocele at the cannulation site, delayed wound healing, surgical resection of a femoral artery aneurysm, and lower limb paresthesia can occur for up to 39 months.¹⁵

ECMO can also result in a lower quality of life for long-term survivors.^{15,16,18} Long-term survivors have been reported to have significantly lower Short-Form 36 (SF-36) physical and psychological domain scores when compared with a healthy population.^{13,16} Survivors can also have difficulty returning to a normal work schedule; in one study 28% of survivors had not returned to work 17 months following discharge from the ICU.¹⁶ ECMO survivors often develop anxiety, depression and post-traumatic stress disorder (PTSD).^{13,18} One study showed scores from the SF-36 for “role limitation due to physical problems,” “general health,” and “social functioning” were significantly lower for ECMO survivors than their healthy counterparts.¹⁵ Moreover, when these patients were divided into two groups based on number of months since hospital discharge, with the exception of the “mental health” score, quality of life scores were lower for patients discharged from the hospital less than 11 months, compared to the patients discharged for a longer time.¹⁵

Early identification of these problems can aid in patient recovery. Thus, it is useful to conceptualize the impact of ECMO on a health trajectory, as this provides a comprehensive means to link a patient's past, present, and projected future health condition and places the patient's health within a specific context.¹⁹ The ultimate goal of outcomes research is the development of evidence-based interventions to meet a variety of needs, to improve quality of life, and to prevent or enable patients to recover from associated complications. Although information regarding quality of life for ECMO survivors is available, there is little data regarding the resulting health problems that affect quality of life for this population. This qualitative study explored the problems and health needs of patients who had been weaned from ECMO during a one-year period following hospital discharge. An understanding of patients' health needs as well as physical, psychological, and social problems that occur after discharge from the hospital will provide insight into additional treatment needs and help health care providers develop care plans suited to this group of patients.

Methods

A qualitative design, incorporating in-depth semi-structured interviews, was used to collect descriptions of the problems and health needs of adult recipients of ECMO following hospital discharge. A qualitative descriptive design was selected to understand ECMO survivor's experiences of their illness after hospital discharge over a one-year period and produce findings that are closer to the data.²⁰

Patients were recruited by purposive sampling from thoracic and cardiovascular wards in two medical centers in northern Taiwan prior to discharge. Attending doctors recommended patients eligible for the study to the researcher. Inclusion criteria were: patients had exhibited signs of acute refractory cardiogenic

shock, cardiac arrest, or respiratory failure and, as a result, received ECMO cardiopulmonary support; ≥ 20 years old (the legal age of adults in Taiwan is 20); spoke Mandarin or Taiwanese; and were willing to participate in a research interview. Presence of cognitive impairment excluded patients from participating. After patients agree to participate in the study, but prior to discharge, we collected their telephone number, demographic data and self-perception of disease severity (on a scale of 0–10, 10 = extremely severe). Clinical data was obtained from the participant's chart with their permission.

Data were collected from 14 participants in audio-recorded, semi-structured face-to-face interviews in participants' homes and the outpatient department of two medical centers from March 2012 to August 2013. Because prolonged engagement can yield important insights and ensure trustworthiness,²¹ each participant was interviewed on four occasions, three months apart, to understand their changing experiences. The first interview was conducted 3 months following hospital discharge; all interviews focused on participants' problems and health needs after being discharged and followed an open-ended semi-structured interview guide (see Table 1). Prompt questions were used with additional questions triggered by participants' responses. Each audio-recorded interview took approximately 30–50 min. The first author conducted the 56 interviews. After each interview, the first author immediately summarized the interview content, noted the participant's responses and confirmed this information with the participant.

Approvals for the study were obtained from the two hospitals' investigational review boards (Approval number, Hospital A: 100-3191B; Hospital B: 1-101-05-037). The first author explained the study's purpose to the recruited individuals, informed them that they could withdraw at any time without any reason or suffering any consequences and assured them that their data would be kept confidential. After patients received this information and agreed to participate they signed a written informed consent. To ensure confidentiality, the tapes were transcribed without the names of participants. Participants were made aware that they were free to withdraw from the interview if any question made them uncomfortable.

Interviews were analyzed from transcripts of the audiotapes, transcribed verbatim by a research assistant and checked by the first author. Data collection was performed concurrently with data analysis. Data collection was discontinued when it was determined that data saturation had been achieved.²² Saturation was established after interviewing participant 13, however one more patient was interviewed to confirm saturation. The researchers analyzed the data according to Miles and Huberman's three-step data analysis process: (1) coding the data and data reduction, (2) displaying the data, and (3) drawing and verifying conclusions.²³ All data were manually coded. Researchers read the interview transcripts several

Table 1
Interview guide.

General questions:

1. Please briefly describe your current physical condition.
2. What is the difference in your physical condition, as compared to how it was at the time of your last interview?

Specific questions:

1. Do you think these problems are related to the ECMO that you received during your hospital stay? Please explain.
2. Do these problems affect your mood? Please give some examples.
3. From the time of your hospital discharge to the present, what problems have you had to face in your daily life or work? Please give some examples.
4. To improve your quality of life, what types of support or assistance do you think you need from health care professionals or family members?

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