

CADTH Health Technology Review

Extracorporeal Membrane Oxygenation for Adults and Children With Severe Respiratory Failure

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Abbreviations

ECMO	extracorporeal membrane oxygenation
ICU	intensive care unit
VA	veno-arterial
VAD	ventricular assist devices
VV	veno-venous

Key Messages

- This review used a framework analysis to synthesize 9 included studies on the perspectives and experiences of patients, family members, and providers on extracorporeal membrane oxygenation (ECMO).
- Patients' perspectives on their experiences are limited due to their sedated status when treated with ECMO.
- Supporting a relative treated with ECMO is stressful for family members. They feel anxious and worried about their relative because of the patient's critical condition, and they struggle to juggle multiple roles at work and home while supporting their relative receiving ECMO.
- Family members often have to travel to see their critically ill relative. Financial and logistical support for temporary relocation near the ECMO centre may ease the burden of travel.
- Family members benefit from clear and frequent communication from health care providers as a source of support and reassurance while their loved ones are being treated with ECMO. There may be a role for informal or formal peer support for family members of patients receiving ECMO.
- Clinicians' decisions to offer, continue, and withdraw ECMO are based on their assessments of prognostic factors from patients' medical histories and clinical conditions. Additional clinical research and/or refinements of prognostic guidance for ECMO may further support evidence-informed decision-making around ECMO.
- Patients, family members, and clinical team members may differ in their assessment of the limits of ECMO treatment and the decision to transition from active treatment to the withdrawal of life support. These findings point to the role of ethical considerations and processes when engaging in transitioning to end-of-life support in the provision of ECMO.
- After discharge, patients who had received ECMO and their family members continued to have feelings of anxiety, intrusive thoughts, and a need to process the event. ECMO programs that can offer continued or ongoing support or referral for patients and their family members' mental health may help address these needs.

Context and Policy Issues

Extracorporeal membrane oxygenation, or ECMO, is a form of life support technology used in situations of critical, life-threatening illness. By circulating the patients' blood through an artificial "lung" or membrane, it delivers oxygen and removes carbon dioxide to meet the patient's metabolic needs.¹ There are 2 primary types of ECMO delivery based on clinical needs. Veno-arterial ECMO (VA ECMO) is primarily for those patients with cardiac or cardiopulmonary failure or in need of cardiac or cardiopulmonary support. Veno-venous ECMO (VV ECMO) is administered to those patients with respiratory failure or in need of respiratory support. Typically, ECMO is used to provide time for the patient to recover, as a bridge to organ transplant, or to enable other surgeries or therapies.¹

ECMO is resource-intensive procedure that requires large, multidisciplinary teams and constant one-on-one nursing care, typically offered in intensive care units (ICUs) in urban settings. Patients are often referred to ECMO following a rapid and critical decline in their condition, and clinicians have to assess the patient and decide on a course of treatment under pressure. Patients are often critically ill and sedated; therefore, family members are

often involved in treatment decision-making.¹ Once on ECMO, multiple complications can arise, including bleeding at the site of the cannula(s), cerebral hemorrhage or stroke, organ failure, lung injury or failure of lung recovery, and infection.¹ Because the treatment requires being stationary in an ICU, further complications include skin or pressure ulcers, infection, pain, and, if not sedated, delirium and fear. Long-term consequences of ECMO include muscle loss, pain at the site of the cannula, and psychological consequences such as anxiety and depression.

There is growing interest in ECMO nationally and internationally. The Extracorporeal Life Support Organization, an international voluntary registry, reports a growing number of adults worldwide who underwent ECMO over the past decade.² Recently, ECMO has been used to treat COVID-19 patients with severe respiratory failure during the pandemic. This has led to additional pressures on ECMO centres and highlighted the potential role of ECMO in the treatment of COVID-19.^{3,4} The purpose of this report is to provide insights from the qualitative literature on the perspectives of those engaging with ECMO, including patients, their family, and their caregivers to support decision-making around the provision and delivery of ECMO for respiratory failure.

Research Questions

1. What are the experiences and perspectives of adults and children with severe respiratory failure and their families on being offered, receiving, and recovering from ECMO?
2. What are the experiences and perspectives of health care providers on offering, providing, and supporting patients' recovery after ECMO for severe respiratory failure?

Methods

Literature Search Methods

A limited literature search was conducted by an information specialist on key resources including MEDLINE and PsycINFO via OVID and CINAHL via Embase. The search strategy comprised both controlled vocabulary, such as the National Library of Medicine's MeSH (Medical Subject Headings), and keywords. The main search concept was extracorporeal membrane oxygenation. CADTH-developed search filters were applied to limit retrieval to qualitative studies. When possible, retrieval was limited to the human population. The search was also limited to English-language documents published between January 1, 2010, and May 5, 2021. Internet links were provided if available.

Selection Criteria and Methods

One reviewer screened citations and selected studies. In the first level of screening, titles and abstracts were reviewed and potentially relevant articles were retrieved and assessed for inclusion. The final selection of full-text articles was based on the inclusion criteria presented in Table 1.

Exclusion Criteria

Publications were excluded if they did not meet the selection criteria outlined in Table 1, they were duplicate publications, or were published before 2010.

Critical Appraisal of Individual Studies

The critical appraisal was conducted by the primary reviewer who followed Krefting's⁵ approach for assessing trustworthiness in qualitative research. The trustworthiness of the study results was evaluated by asking questions about how the research methods shaped how the research team arrived at their findings or results. This was done with a particular focus on 4 guiding questions:

- Were the study authors true to their participants (credibility)?
- Does the analysis make sense in light of the data presented (confirmability)?
- Is the analysis consistent across study findings (dependability)?
- Is the analysis relevant to the research question of this review (transferability)?⁵

Results of the critical appraisal were used to understand the methodological and conceptual limitations of the included publications in specific relation to the research questions. The results of the critical appraisal are reported narratively; general notes on trustworthiness and transferability (i.e., high, moderate, low) are reported in Table 2 in Appendix 2.

Data Analysis

A framework analysis was used to organize and analyze results of the included studies.⁶ The a priori framework consisted of concepts from project scoping and the research question, largely orienting the analysis along the process of being offered or receiving ECMO, undergoing ECMO, and withdrawing and recovering from ECMO. Additionally, the type of participant (i.e., patient, family member, health care provider) was considered when conducting the analysis.

One reviewer conducted the analysis. Included primary studies were read and re-read to identify key findings and concepts that mapped on the framework, which was modified as new concepts emerged. During the reading and re-reading of studies, analytic memos were made, noting details and observations about the study's methodology, findings,

Table 1: Inclusion Criteria

Criteria	Description
Sample	Adults and children with severe hypoxic and hypercarbic respiratory failure, their family members, and health care providers
Phenomenon of interest	Extracorporeal membrane oxygenation (veno-venous and veno-arterial)
Design	Any qualitative design
Evaluation	Views and experiences of being offered/offering, receiving, and recovering from extracorporeal membrane oxygenation
Research type	Primary qualitative studies; qualitative component of mixed-method studies (excluding surveys)

and interpretations, and connections to other studies and concepts in the framework. Diagramming was used to explore how emerging concepts mapped across study findings and across concepts. Using these techniques, concepts were re-ordered and organized into thematic categories. Re-reading, memoing, and diagramming continued until themes were appropriately described and supported by data from the included publications. During the analysis, issues with transferability and the results of the critical appraisal were reflected on to aid with interpretation. The objective of the analysis was to identify and describe categories of findings that offer insight into the experiences with and perspectives on ECMO from patients, their family members, and health care providers.

Summary of Included Literature

Quantity of Research Available

A total of 355 citations were identified in the literature search. Following screening of titles and abstracts, 345 citations were excluded and 10 potentially relevant reports from the electronic search were retrieved for full-text review. Of these potentially relevant articles, 1 publication was excluded (non-English full-text article), and 9 publications met the inclusion criteria and were included in this report. Appendix 1 presents the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA)⁷ flow chart of the study selection.

Summary of Study Characteristics

Additional details regarding the characteristics of included publications and their participants are provided in Appendix 2.

Study Design, Data Collection, and Data Analysis

Three studies used a descriptive qualitative design,⁸⁻¹⁰ and 2 studies did not report the type of study design used.^{11,12} One study each used the following: focused ethnography,¹³ grounded theory,¹⁴ and interpretive phenomenology.¹⁵ One study used a mixed-method convergent parallel design.¹⁶

Six studies collected data using semi-structured or in-depth interviews.^{8-10,12,14,16} One study collected data using observations and interviews,¹³ and another used interviews and documents.¹¹ One study collected data using focus groups.¹⁵

Four studies analyzed their data using thematic analysis.^{8-10,15} One study each used the following: descriptive abductive,¹³ content analysis,¹¹ qualitative descriptive,¹⁶ Miles and Huberman's 3-phased analysis,¹² and grounded theory.¹⁴

Country of Origin

Of the 9 included studies, 3 were conducted in Australia,^{9,10,15} 2 were conducted in the US,^{11,13} and 1 each in the State of Kuwait,⁸ Turkey,¹⁶ Taiwan,¹² and UK.¹⁴

Study Participants

Three studies included health care providers who care for adult patients using ECMO.^{8,11,15} Three studies included adult participants who had themselves received ECMO.^{9,12,16} Two

studies included family members who had supported an adult who had received ECMO.^{10,14} One study included clinicians and family members of patients receiving ECMO.¹³

Interventions

Four studies were focused on ECMO broadly (VV and VA).^{9-11,13} Two studies did not specify which type of ECMO was involved,^{12,16} whereas 2 studies focused on VV only.^{8,14} One study included both ECMO (not specified) and ventricular assist devices.¹⁵

Summary of Critical Appraisal

Overall, the set of included studies were judged to be of moderate to high in terms of their trustworthiness. Of the included studies, 5 were assessed as moderately trustworthy^{8,11,12,15,16} and 4 as highly trustworthy.^{9,10,13,14} The studies assessed as moderate quality typically reported findings that were superficial or underexplored, or findings that were not richly described and supported by data.^{8,11,12,15,16}

All studies were transferable in terms of their study setting and population. However, in 3 publications, transferability was limited due to a research focus that was less relevant to the research questions guiding this report.^{11,12,16}

Results

ECMO Initiated by and During Crisis

Family members and patients reported that a dramatic and sudden decline in the patient's condition precipitated being offered ECMO.^{9,10,14} It was in this context of an urgent crisis that family members were asked to be surrogate decision-makers for the patient.^{9,13,14} This was typically because the patient was unable to provide consent due to being sedated or otherwise non-responsive.¹³

Family members described agreeing to ECMO, seeing it as buying time for recovery and as a lifesaver.¹³ In this way, family members saw ECMO as offering hope.^{9,13,14} Several family members described ECMO not as a choice, but as necessary, as the alternative was "near-certain death (p. e5)."¹³ As 1 family member described it, "[i]t was clear it was her only chance so it wasn't a case where you've got a choice (p.13)."¹⁴

Physicians also described seeing ECMO as buying time and as offering hope, but their perspective on individual cases was more uncertain or tentative: "For attending surgeons and intensivists this uncertainty was exacerbated by a feeling of being pressured to use ECMO frequently by other clinicians and by high family expectations despite the difficulty of obtaining a full picture of patient status pre-intervention (p. e5)."¹³ Physicians reported pressure to initiate ECMO to prevent death even as they lacked a comprehensive picture of the patients' clinical condition.¹¹ As with family members, physicians and providers had to make quick decisions and act to save patients, often working with competing pressures and limited prognostic information.^{11,13}

ECMO as Escalating Intervention

Time stopped for patients who were on ECMO as they were generally sedated and could not recall their ICU stay.^{9,10} Yet it carried on for their family members, who described it as a period of great stress, fear, and worry. As a partner of a patient who received ECMO described it: "...

really, in a way it's a good thing that he wasn't awake to experience all of that trauma and stress. I mean, it was really up to me and [patient's] sisters to bear that, but, yeah... (p. 1160).⁹

Watching their loved ones on ECMO and changes in their condition or complications was emotionally and psychologically difficult for family members. ECMO treatment unfolded in front of patients' family members without them knowing what to expect with each passing day: "...coming in every day and seeing him hooked up to all those machines, it was so traumatic for me...ECMO machine is lifesaving, it can also be damaging to the brain, and I had no idea that was the case. And when they told me that, that was then the next trauma... (p. 1660)."⁹

When physical changes or complications were taking place (e.g., mottling, overt bleeding), family members described being disturbed and anxious and worried.^{9,13,14} Throughout the intervention period, family members struggled with anxiety and the feeling that death was close at hand.^{9,16} During the stay in the ICU, there were moments of proximity to death "... because there were three separate occasions that I was told, 'Bring family in if you want them to say goodbye to him' (p. 1160)."⁹

If family members raised worries about the limits of treatment, it was reported that clinicians "attributed family skepticism about continued escalation to inexperience; these surrogates, they explained, lacked the prognostic and interventional expertise to know whether the care ceiling had truly been reached (p. e5)."¹³ Relatedly, some clinicians described that they saw initial consent to ECMO as consent to aggressive care: "Once you sign that paper and once you make that decision to go on ECMO, it kind of comes with a commitment. So, it's not [as if] you go on ECMO and if in two days things are not working out we're going to take it off and let you pass peacefully... You're signing and giving your loved one over to us – and let us take this on and let us see what we can do (p. e5)."¹³

Yet this was not universally held by all clinician participants. One clinician observed that: "[e]verything we did just caused more complications...like losing your limbs or having a stroke or coding. I question, what are we actually doing? Are we actually treating this person like a human being or is (the patient) becoming a lab experiment (p. 3-4)."¹¹ In this same study (evaluating the ethics consultation protocol), particular cases were evoked by clinicians during interviews. Clinicians referred to "extreme procedures, amputation of limbs, and dyspnea and anxiety for those awake and alert patients stranded on ECMO (p. 3)."¹¹ It was clear in clinicians' descriptions that they saw ECMO as involving suffering for their patients.¹¹

Coping and Waiting During ECMO

In this context of escalating care and waiting, nurses who provided intensive one-on-one care to ECMO patients sought to build a connection with their patients.^{8,15} This was particularly because of how critically ill they were and that their prognosis was uncertain: "...do the best to improve their life while they're waiting – because they could have a stroke the next day and die (p. e12)."¹⁵ Empathy, for nurses, was seen as enabling the provision of more tailored care in the context of ECMO, and that forming a connection was a key part of providing support and comfort, and was experienced as rewarding. Nurses described that "backing off emotionally is sometimes hard, particularly if you actually really like them (p. e13)."¹⁵ The intensity of the care and depth of the connections to their patients were pointed to as playing a role in compassion fatigue and burnout. Also contributing to burnout was a full caseload of high-need patients^{8,15} "...but also full on families; dealing with the emotional side of ECMO or VAD [ventricular assist devices] in someone acutely ill with families...who don't get along

or who don't understand what's happening (p. e13).¹⁵ Thus, while family members played an important role in supporting patients, they could at times complicate the role of those providing nursing care.

Family members were involved in patients' daily care when they could. This involved supporting patients and communicating with clinicians. Family members varied in their level of engagement with medical information,^{9,13} but in all cases saw communication with the clinical team as an essential source of support and coping:

The most important thing is communication to the family... Even if there's nothing happening, just let the family know that nothing's happening... Honestly is the best because when you get in there and you see your family member hooked up to machines, and things beeping, and stuff going on, and nurses running around like headless chooks, they just need to know that's nothing's happening... (p. 1664).⁹

Many family members took photos, wrote in a diary, or otherwise documented their time in the ICU as a way of coping and to have something to show their loved one, other family members, or relatives.^{9,10}

Distance from the ECMO centre and their home was particularly hard for family members to cope with, forcing them to either temporarily relocate close to the hospital or spend time away from their critically ill loved one.⁹ Adult family members with young children or other caregiving responsibilities often felt torn between tending to those responsibilities and their critically ill relative,⁹ and they had to juggle multiple roles and manage their life around their critically ill family member:

Yeah, it was kind of a juggle. So, I was still working 3 days a week and I was just trying to organize people to look after my kids... I was there every day that I wasn't at work... I sort of shared myself around between my two brothers that live down there and just at hotels and stuff...financial responsibility was a lot of pressure, but I've never got into a situation where things went really bad... (p. 1661).⁹

Some family members described drawing on other ECMO families for support. However, these experiences were not equivocally positive because sometimes seeing another family cope with the death of a loved one or other changes in condition led to distress and worry. They do suggest that peer support can be a way that family members of patients receiving ECMO can get support, but that they can also cause distress and worry.^{10,14}

Reaching the Limits of Treatment and Withdrawing ECMO

In cases where the patient failed to recover, views on who has the authority and/or the responsibility to make the call to continue or discontinue ECMO differed across providers, and between providers and family members.^{11,13}

In a study focused on evaluating the use of an ethics consultation protocol, providers reported how the protocol helped resolve conflicts between treatment teams.¹¹ In other cases, providers described coming to an agreement among themselves when limits of treatment had been reached.¹³ Here, they communicated their decision to family members 1 to 2 days after they reached an agreement.¹³ This points to the way that the clinical teams supporting ECMO patients required time to negotiate and decide the limits of treatment among themselves before involving family members.

Providers in a study evaluating an ethics consultation protocol felt it was helpful because it made the failure of treatment transparent and the decision to stop ECMO non-negotiable to the family.¹¹ One provider described this need for transparency and non-negotiability further: “[f]or this family...they will not be able to make the decision [to stop ECMO] on their own accord unless clearly told the patient/medical team has reached the point we talked about when the fight is lost and it is ethically wrong to keep supporting [the patient’s] body with devices intended for short-term use (p. 3).”¹¹ In other cases, however, clinicians deferred to families to withdraw life support “attributing this shift in authority [to decide to withdraw ECMO] to families’ familiarity with their ‘loved one’s wishes’(p. 6).”¹³ This suggests clinicians may, in some cases, anticipate resistance from or differing opinions with family members (likely depending on the family/patient). Different justifications for the decision to withdraw life support, whether the patients’ clinical status or the patient’s wishes or what is best for them, may help clinicians and families alike justify the decision.

During this transitional period, clinicians described making minor care adjustments “expressing the importance of families witnessing clinicians ‘doing something’ while they gradually came to terms with the inevitability of withdrawal (p. 6).”¹³ When faced with making decisions about withdrawing treatments, family members were described as putting the responsibility for decisions onto patients’ clinical status.¹³ Family members found reassurance in the idea that they had exhausted all options for saving their loved one.¹³

When a patient on ECMO died, clinicians saw it as due to the limitations of existing patient selection criteria; in other words, in looking back, they saw that patient to be a poor candidate for ECMO.¹³ This highlights again the ways that the lack of needed information for an accurate prognosis affected physicians’ ability to make evidence-based clinical decisions around continuing ECMO and its withdrawal.¹¹

Recovery From ECMO and Discharge to Home

With the successful withdrawal from ECMO, a whole set of new challenges awaited patients and their family members. Patients were often described as being delirious upon regaining consciousness, which was hard for both patients and their family members.¹⁴ When their loved one was first coming to, a family member described how “[h]e was dribbling and looked brain damaged...he said he had all these big red crabs all over him and wanted us to knock them off. That was funny yet frightening, well it’s funny now but it wasn’t funny at the time (p. 14).”¹⁴ As patients withdrew from sedation, they confronted their limited physical mobility due to muscle loss and weakness from prolonged bed stay¹⁶: “The only thing that I probably dreaded the most was the physio because my legs were really — I couldn’t even do a simple thing like lifting my arms above my head. And that was the hardest thing because my legs were like rocks. I couldn’t move my ankles or anything (p. 222).”⁹

Being transferred out of the ECMO unit was cited as a hard experience for family members.¹⁰ This was because they felt that the new unit and ward staff had no appreciation for how critically ill their relative had been and the seriousness of their condition,¹⁰ but also that they felt that no one knew the patient to coordinate their care.¹⁰ Patients described wanting more support for early discharge to help them return to being as active as possible.¹⁶ They also desired in some cases for more information to help support them once they returned home: “It would have been nice if they had told me what to eat and what kind of activities to do and had helped me get rid of my fears and worries about the wound site after I had been discharged (p. 596).”¹⁶ Some noted that travel to the multiple follow-up appointments post-discharge remained a challenge because of the required time, coordination, and expenses.¹⁰

Back at home, a host of physical challenges remained: patients described living with continuing pain and numbness and that they lacked the ability to do many basic activities of daily living (e.g., basic self-care, eating, toileting, bathing).⁹ This led to continued dependence on others, particularly their family members who continued to play a central role in their care. For some, limitations in their mobility meant that they could not return to work or live as they once did, including in their own home: "I cannot stay in my home anymore because I cannot climb up five floors, so I have to stay with my son (p. 596)."¹⁶ For others, these limitations meant that they could no longer engage in activities that gave them personal pleasure: "Yeah well that was the same old thing, she just sort of said 'I got this up here, and I can't do what we did before, I can't play basketball, I can't play tennis,' and she was just going on. She put on a couple of kilos — Yeah she did get a little bit depressed that she just couldn't do what she did before... (p. 1663)."⁹ Some people described socially withdrawing post-ECMO and struggling to connect with others because of their hoarseness or mobility limitations.¹² These experiences highlight the ways in which their critical illness continued to affect their lives in a multiplicity of ways even after discharge.

Family members talked about how stressful and traumatic it had been to watch their loved one almost die and receive ECMO. Many described how the experience still affected them, that they remained scared and, at times, had intrusive thoughts.¹⁴ Although this was described less often by people who had received ECMO, they too reported nightmares and the inability to forget their experience.⁹ Many used the diaries, photos, and documentation from their family members to understand what they had gone through and to fill in their memory gaps: "[s]o we had our own running timeline that I've gone back and read over. Even though I was unconscious, it's still painful to read, evokes a lot of emotions (p. 224)."⁹

Family members described being unable to talk about the experience with their loved one who had undergone ECMO because they did not want to talk about it or remember it or, when they did listen, they were not able to relate to the supporting relatives and/or the experience.^{10,14} This was corroborated by some patients themselves: "I do not recall and I do not want to. I don't even like the idea of the fact that I had tubes down my throat. I had the gastric feeding tube into my nose, and I absolutely hated that... (p. 223)."⁹ Among study participants, there was no mention of the support that family members and people who had received ECMO were receiving for their psychological and emotional concerns. However, in the 2 studies in which family members shared these views, both found that they welcomed the opportunity to talk and saw the interview process itself as valuable for being able to tell their story.^{9,14}

Limitations

The primary limitation of this review is the small set of included studies. No studies were identified that described the experiences of family members or health care providers caring for pediatric patients receiving ECMO. Further, only 1 study included family members of patients who did not survive ECMO; the views and experiences of these family members are also important to consider. Patient participants were likely to be healthier than non-participants,¹⁰ so findings related to ECMO survivorship are not necessarily transferable to those who live with functional disability following ECMO (whether due to ECMO or their underlying condition). None of the included studies included information about those patients or their family members who were offered but did not choose ECMO. As a result, the findings reported here should be interpreted with these limitations in mind and, specifically, that they do not encompass or capture all experiences related to ECMO.

Conclusions and Implications for Decision- or Policy-Making

This review used a framework analysis to synthesize 9 included studies on the perspectives and experiences of patients, family members, and providers on ECMO for respiratory failure. The review found that although ECMO was initially seen as a lifesaving intervention offering hope in a time of crisis, it marked the beginning of an uncertain journey for family and clinicians as they waited to see if the patient would recover. When patients did not recover, family members consoled themselves by knowing that they did everything they could, whereas clinicians tended to see it as a failure of their patient selection. When patients recovered, they and their family members continued to confront physical, psychological, and emotional challenges even after discharge.

Family members who are important supports for patients receiving ECMO often have to travel to see their critically ill relatives. Financial and logistical support for temporary relocation close to the ECMO ICU may ease the burden faced by some family members. Family members also have varying information needs and may benefit greatly from clear and frequent communication as a source of support and reassurance. Additional opportunities to support families and relatives of patients receiving ECMO may lie in the role of informal or formal peer support for family members.

Clinicians' decisions to offer, continue, and withdraw ECMO are based on their assessments of prognostic factors from patients' medical histories and clinical conditions. Having a full clinical picture is likely to help decision-making, as is further refinement and understanding of ECMO prognostic trajectories. This suggests that advancing clinical research on ECMO prognosis is likely beneficial to support evidence-informed decision-making around the provision of ECMO.

Patients, family members, and clinical team members may differ in their assessment of the limits of ECMO treatment and the decision to transition from active treatment to the withdrawal of life support. Although these decisions may be supported through improved prognoses, the findings point to the role of ethical considerations and processes when engaging in transitioning to end-of-life support in the provision of ECMO. Opportunities may exist to develop or implement standardized protocols that facilitate transparent and ethical decision-making around ECMO for all involved.

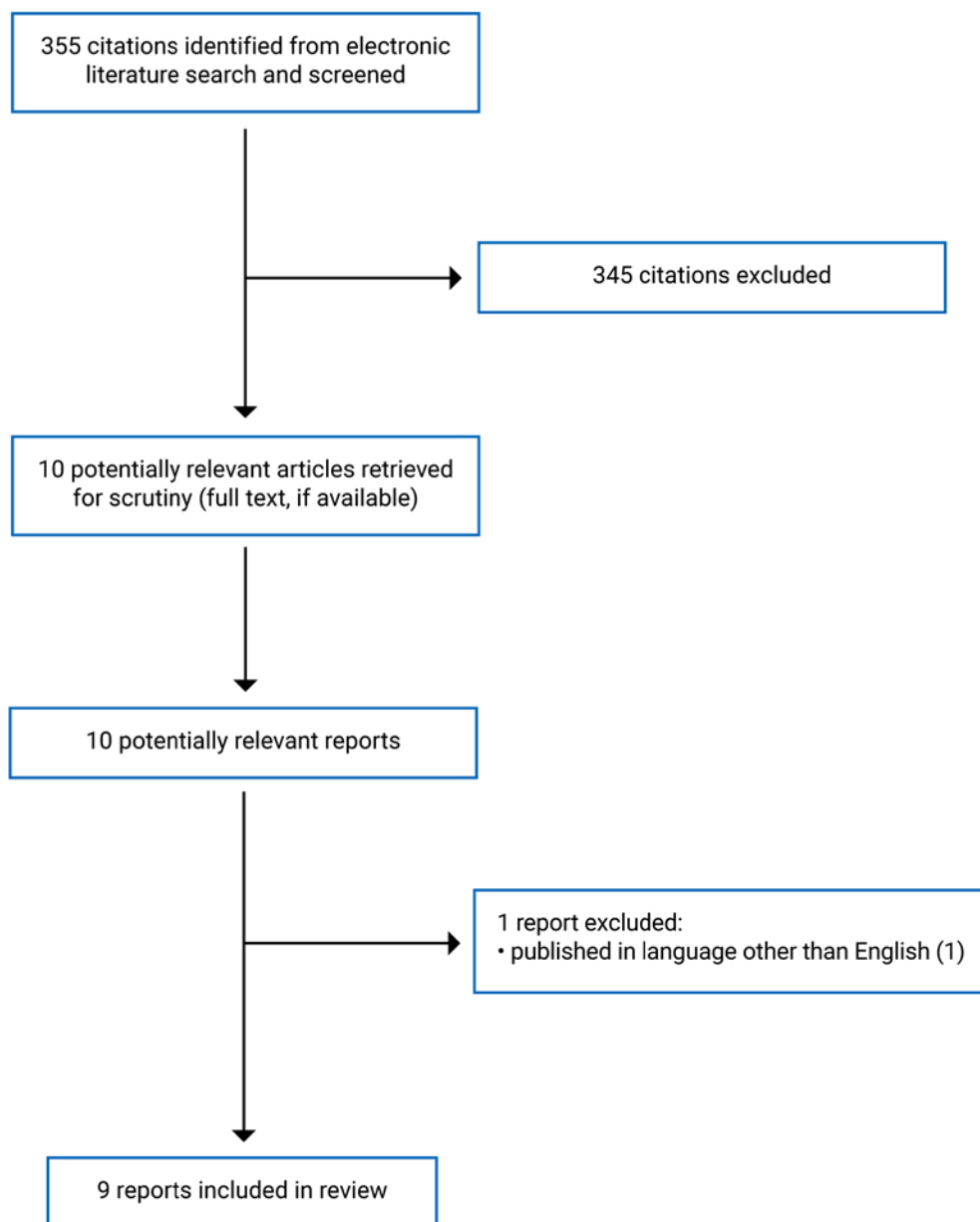
The transfer from ECMO to another ward or unit was found to be highly disruptive for many families. Families and patients will likely benefit when there is communication between care teams during transitions to ensure coordination of care. Post-discharge, patients and family members continued to recover from the physical, psychological, and emotional impact of the critical illness and the ECMO. Findings about lingering feelings of anxiety, intrusive thoughts, and the need to tell of their experiences speak to a potential unmet emotional and/or psychological need in ECMO survivors and their family members. ECMO programs that can offer continued support or referral for support may help address this unmet need.

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Appendix 1: Selection of Included Studies

Figure 1: Selection of Included Studies



Appendix 2: Characteristics of Included Publications and Their Participants

Table 2: Characteristics of Included Publications and Their Participants

Author (year), country	Study objectives	Study setting	Description of study participants	Study design, method of data collection and analysis	Judgment on trustworthiness and transferability
Hadler et al. (2021)¹³ US	To describe decisions about the escalation and withdrawal of treatment from patients on ECMO (VA and VV)	2 cardiothoracic ICUs in 2 US academic hospitals	13 clinicians (surgeons, intensivists, nurse practitioners, critical care nurse, house staff) 25 family members of patients who received VA (n = 9) or VV ECMO (n = 11)	Focused ethnography; observations and weekly interviews with families during patient's time on ECMO (maximum of 4 interviews) and unit clinicians; descriptive abductive	High: Multiple types of data sources used, multiple points of data collection, methods and findings well-described. Study objective and setting are highly transferable to this review.
Wirpsa et al. (2021)¹¹ US	To evaluate a protocol for early and routine ethics consultation protocol for patients on ECMO (VA and VV)	A dedicated ECMO unit in a Midwest academic medical centre	20 multidisciplinary providers (physicians, fellows, advanced practice providers, general and specialist nurses)	NR; interviews and documents (ethics consultation forms); content analysis	Moderate: Uses 2 data sources, very much on the deductive descriptive end of qualitative research. The focus on the ethics consultation protocol limits the transferability (relevance) of some of the findings.
Alshammari et al. (2020)⁸ State of Kuwait	To understand nurses' perspectives on their role and their competencies and challenges caring for patients receiving VV ECMO	An adult ICU with ECMO in a general hospital	19 nurses who had provided care to patients receiving VV ECMO	Descriptive qualitative study; semi-structured interviews; thematic analysis	Moderate: The methods are well-described; however, the findings are not well-developed and are were not richly described. Study objective and setting are highly transferable to this review.

Author (year), country	Study objectives	Study setting	Description of study participants	Study design, method of data collection and analysis	Judgment on trustworthiness and transferability
Savas et al. (2020)¹⁶ Turkey	To describe the experiences of ECMO patients including problems and quality of life post-discharge	Cardiovascular surgery ICUs of 2 state hospitals	People who had received ECMO (not specified) and who had been discharged for at least 1 month	Convergent parallel mixed-method study; semi-structured interviews post-discharge; qualitative data analyzed descriptively	Moderate: Focus is on describing physical experiences, not meaning of them to patients. Minimal accounting of duration since discharge in patients' experience. The focus on identifying post-ECMO physical problems (not their meaning) limits the transferability of this study to this review.
Wrigley et al. (2018)¹⁵ Australia	To explore the challenges and experiences of nursing providing mechanical circulatory and respiratory support (including ECMO) to develop interventions to support them	5 hospitals which provided mechanical circulatory and respiratory support	9 mechanical circulatory and respiratory support nurses who specialized either in VAD or ECMO	Interpretive phenomenology; focus groups; thematic analysis	Moderate: Overall study methods and findings well-described and supported. Unclear how participants were recruited and selected, and if a form of saturation was reached. Study objective and setting are highly transferable to this review.
Tramm et al. (2017)¹⁰ Australia	To explore the experiences of family members of patients treated with ECMO	A prospective cohort study of health outcomes conducted at 1 Australian hospital	10 family members of patients who had received ECMO and had completed a health survey 12 months post-discharge as part of the larger cohort study	Qualitative descriptive; semi-structured interviews; thematic analysis	High: Methods well-described and consistent with qualitative descriptive analysis. Findings are theoretical and empirically rich. Study objective and setting are highly transferable to this review.

Author (year), country	Study objectives	Study setting	Description of study participants	Study design, method of data collection and analysis	Judgment on trustworthiness and transferability
Chen et al. (2016)¹² Taiwan	To explore problems and the health needs of adults who received ECMO in the 12 months post-discharge	Thoracic and cardiovascular wards from 2 medical centres	14 participants who had received ECMO (not specified)	NR; longitudinal qualitative interviews (4 interviews, 3 months apart), qualitative analysis informed by Miles and Huberman's 3 phases	Moderate: Study and findings are well-described. Strong data collection methods to be able to track changes over time. Lack of exploring the impact or meaning of health status for participants weakens the findings. The focus on identifying physical symptoms following ECMO limits the transferability of this study to this review.
Tramm et al.^a (2016)⁹ Australia	To explore the acute care experience of patients receiving ECMO (VA and VV)	A prospective cohort study of health outcomes conducted at 1 Australian hospital	10 ECMO survivors (7 VA ECMO, 3 VV ECMO) who had completed a health survey 12 months post-discharge as part of the larger cohort study	Qualitative descriptive; semi-structured interviews; thematic analysis	High: Methods well-described and consistent with qualitative descriptive analysis. Findings are theoretical and empirically rich. Study objective and setting are highly transferable to this review.
Harris-Fox (2012)¹⁴ UK	To describe the experiences of the relatives of adult patients receiving ECMO within a clinical trial	Clinical trial in an UK ECMO unit	14 family members of patients who had received ECMO within the last 12 months	Grounded theory; in-depth interviews; grounded theory	High: Methods and findings well-described, consistent with grounded theory. Study objective and setting are highly transferable to this review.

ECMO = extracorporeal membrane oxygenation; NR = not reported; ICU = intensive care unit; VA = veno-arterial; VAD = ventricular assist devices; VV = veno-venous.

^aTramm et al. (2017)¹⁰ and Tramm et al. (2016)⁹ are part of the same larger prospective cohort study but use separate data.