



Experiences of adult extracorporeal membrane oxygenation patients following discharge: A mixed methods study



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ABSTRACT

Background: Survival and discharge rates after extracorporeal membrane oxygenation are gradually increasing. More research is warranted to investigate extracorporeal membrane oxygenation patients' post-discharge experiences, problems and quality of life.

Objective: The aim of this study was to determine adult extracorporeal membrane oxygenation patients' experiences, problems and quality of life following discharge.

Methods: A mixed methods research was used. Study sample consisted of 11 adult extracorporeal membrane oxygenation patients discharged at least one month prior to study entry. In-depth interviews were conducted. Participants' quality of life was assessed using the EuroQol 5 Dimension 5 Level questionnaire.

Results: Two categories (pre- and post-discharge), 7 themes and 16 sub-themes were developed based on in-depth interviews. According to the EuroQol 5 Dimension 5 Level, participants had high perceptions of health.

Conclusion: Extracorporeal membrane oxygenation patients should be provided with comprehensive post-discharge education, exercise programs, social support and regular home visits for post-discharge assessment and follow-up care.

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Introduction

Extracorporeal membrane oxygenation (ECMO) has become a common treatment strategy with increasing clinical experience and technological advances in recent years.^{1,2} According to the Extracorporeal Life Support Organization (ELSO) data, 45,299 adult patients with cardiac, pulmonary and extracorporeal cardiopulmonary resuscitation (ECPR) were treated with ECMO in 2019, and survival and discharge rates after ECMO gradually increased.³ ECMO can last for days or weeks. However, such complications as bleeding, stroke, delirium, acute renal failure, pulmonary embolism, displacement of cannulas, vascular perforation and lower extremity ischemia may develop due to the device, anticoagulant therapy and long bedridden periods.⁴⁻⁷

Patients experience not only ECMO-related problems in the hospital but also physical and psychosocial problems after ECMO and following discharge, which adversely affect their quality of life.⁸⁻¹⁰

Patients discharged after ECMO suffer from various problems such as pain in the lower extremities, paresthesia, ischemia, lymphocele in the cannulation area, delay in wound healing, depression and post-traumatic stress disorder.^{11,12} Although ECMO is becoming more and more common in Turkey as well as in the world, the number of studies on post-ECMO problems and quality of life is limited. The studies on ECMO patients are usually retrospective ones that determine survival rates and ECMO complications, and no research has been conducted on patients' experiences and quality of life after ECMO and following discharge in Turkey.¹³⁻¹⁶ The aim of this study was to determine the experiences and quality of life of adult post-discharge ECMO patients in Turkey. We believe that the results of this study will contribute to ECMO patients' care, discharge planning and post-discharge home care management.

Methods

Design

The study used the convergent parallel design, which is a mixed method, to determine ECMO patients' experiences and quality of life following discharge. In this method, qualitative and quantitative

Abbreviations: ECMO, extracorporeal membrane oxygenation; ELSO, extracorporeal life support organization; ECPR, extracorporeal cardiopulmonary resuscitation; SPSS, statistical package for social sciences; ICU, intensive care unit; VAC, vacuum assisted closure; EQ-5D-5L, EuroQol 5 dimension 5 level; EQ VAS, EuroQol visual analog scale

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methods are used together to examine research problems in a comprehensive and multidimensional way.¹⁷ Qualitative and quantitative data of equal importance are collected simultaneously and independently of each other and analyzed separately and generally brought together for interpretation.^{18,19} The objective of the convergent parallel design is to collect different but complementary data on the same subject matter in order to understand research problems in the best way possible.²⁰ In line with this, semi-structured in-depth interviews were conducted based on the interpretive phenomenology model developed by Van-Manen in order to collect data on ECMO patients' experiences.²¹ In the interpretive phenomenology model, what people experience in common with a phenomenon is transformed into a structure and described with their own words. The researcher makes a description that defines the essence of people's experiences based on his/her own experiences and literature.²¹ The EQ-5D-5 L questionnaire was used to collect quantitative data on quality of life after ECMO.

Participants

The study population consisted of patients treated with ECMO in the cardiovascular surgery intensive care units of two state hospitals and discharged at least one month prior to study entry. Participants were recruited using criterion sampling, which is a non-probability purposive sampling method used to collect qualitative data.^{17,20} This method involves selecting participants who have experienced a specific phenomenon and determining a number of criteria in accordance with the literature and suitable for the purpose of the study. The inclusion criteria were as follows: (1) aged 18 or older, (2) literate, (3) no mental problems, (4) no communication problems, (5) no follow-up due to cardiac failure [ongoing chronic heart failure symptoms may complicate assessment of post-ECMO quality of life] and (6) not using saphenous vein in coronary artery bypass graft surgery [complications such as possible pain, edema, infection and paresthesia due to removal of saphena may be mistaken for complications due to ECMO cannulation]. Sample size was based on data saturation. The data started to be repeated in the 7–8th interviews. After the data started to repeat, 3 more participants were included in the study. Based on this criterion, 11 patients were included until data saturation was reached. Quantitative and qualitative stages were simultaneously performed for the same sample group, and therefore, no further sampling was performed for the quantitative stage.¹⁸

Data collection

In the convergent parallel design, the same sample can be used to derive qualitative and quantitative data simultaneously. In this study, the EQ-5D-5L was administered and semi-structured individual interviews were conducted simultaneously.

Qualitative interviews

In-depth interviews were conducted using a semi-structured questionnaire to collect qualitative data. The questionnaire consisted of 6 open-ended items addressing patients' health perceptions, physical and psychosocial changes, coping mechanisms following discharge and expectations of healthcare professionals during and after ECMO (Table 1). The semi-structured questionnaire was developed by the researchers with ECMO and qualitative research experience based on literature review. An expert in qualitative research was consulted for the questionnaire items. A pilot study was conducted with three patients. No revision was made to the questionnaire after the pilot study.

Table 1
Semi-structured in-depth individual interview questions.

QUESTIONS	
1	How would you explain your post-discharge health status?
2	Do you think that you have ECMO-related post-discharge physical problems? (If so, elaborate, please?)
3	Do you think that ECMO has affected your post-discharge mental health? (If so, elaborate, please?)
4	Do you think that ECMO has affected your socio-economic status after discharge? (If so, elaborate, please?)
5	Could you please explain how you solve your problems or negative situations?
6	Could you please explain your expectations of healthcare professionals during ECMO therapy and post-discharge period?

Quantitative measurement

Quantitative data were collected using the EQ-5D-5L, which consists of two parts; the EQ-5D-5L descriptive system and the EQ visual analogue scale (EQ VAS). The EQ-5D-5 L descriptive system contains five items concerning mobility, self-care, usual activities, pain/discomfort and anxiety/depression. In the EQ VAS, participants rate their health status using a visual analog scale in the form of a thermometer from 0 (worst) to 100 (best). The higher the score, the better the health perception. The Cronbach's alpha of the scale was reported to be 0.80.^{22,23}

Demographic and clinical information

Demographic and clinical information were obtained from patient interviews and medical records. It consisted of two parts addressing (1) demographic characteristics (13 items) and (2) clinical information (13 items).

The study was conducted between 17 April and 10 November 2018. First, a pilot study was performed with 3 patients, and data were included in the study. ECMO was performed in the cardiovascular surgery intensive care units of two hospitals. Patients followed up in the clinic were informed about the purpose and procedure of the study prior to participation, and written and verbal consent was obtained from those who agreed to participate in the study and met the inclusion criteria. During preliminary interviews, the clinical information in the questionnaire was obtained from participant's files and contact information from the participant. The patients who were discharged were contacted by the researcher on the phone at the end of the first month to set a date and time to conduct in-depth interviews in participants' homes. Before interviews, the researcher completed first introductory information questionnaire and then the EQ-5D-5L. Afterwards, in-depth interviews were conducted in a quiet room which made both the interviewer and interviewee feel comfortable and facilitated the interaction between them. The interviews were audio-recorded. The researcher asked probing questions to encourage participants to elaborate on their feelings, thoughts and experiences. Each interview lasted about 30 min (min=13, max=54). The interviews were conducted in Turkish.

Data analysis

The data analysis steps developed by Bazaley for convergent designs were followed. In this method, qualitative and quantitative data are simultaneously collected and independently analyzed, and results are interpreted according to the research questions.²⁴ In the study, qualitative and quantitative data were collected together, analyzed independently from each other and results were interpreted in line with research purposes.

Qualitative interviews

The researcher (HS) transcribed the interviews and listened to the interviews again and reviewed the transcripts to correct errors. Qualitative data were analyzed using descriptive analysis proposed by Strauss and Gorbun.^{25,26} In descriptive analysis, participants'

statements are described in a systematic and clear manner. Then, the descriptions are interpreted, and the cause-effect relationship between them is examined to draw conclusions. The researchers (HS, ZÖK) first read and analyzed the transcripts separately and then scrutinized the transcripts together for similarities and differences and agreed upon 7 themes and 16 subthemes. All participants were assigned codes (from P1 through P11) to maintain confidentiality. Their age (A) and gender (M or F) were also given in parentheses at the end of the quotes, e.g., (P1, 38A, M). The transcription was in Turkish. The context, themes and sub-themes were based on the Turkish texts. At the stage of reporting, participants' statements were translated into English by a native speaker.

Quantitative measurement and demographic/clinical information

Data were analyzed using the Statistical Package for Social Sciences (SPSS) for Windows 22.0. Data analysis included number, percentile, mean and standard deviation calculations.

Ethical considerations

The study was approved by the Non-Interventional Clinical Research Ethics Board of Hacettepe University (Decision No: GO 18/137-11; date: February 6, 2018). Written consent was obtained from the patients. Written permission was obtained from the two hospital management to conduct the study.

Results

Tables 2 and 3 show the demographic and clinical information of the participants, respectively. Their mean age was 43 ± 14.81 years and most of them were male. Seven participants were unemployed. Five participants were treated with ECMO for postcardiotomy cardiogenic shock. The mean duration of ECMO support was 8.64 ± 11.6 days. Nine participants (81.8%) developed various complications during ECMO. The most common complications were bleeding and musculoskeletal problems.

Qualitative

Interview data were analyzed in two categories; pre- and post-discharge (Table 4). The results of interviews showed that ECMO-related problems negatively affected post-discharge life. Therefore,

Table 2
Descriptive characteristics (n = 11).

Descriptive characteristics	$\bar{X} \pm SD$	Min – Max
Age	43.90 ± 14.81	20 – 68
	n	%
Gender		
Male	8	72.7
Female	3	27.3
Marital status		
Married	7	63.6
Single	4	36.4
Education level		
Primary school	5	45.4
Middle School	2	18.2
High school	2	18.2
College	2	18.2
Employment		
Yes	4	36.4
No	7	63.6
Receiving information before ECMO		
Yes	2	18.2
No	9	81.8
Receiving information on discharge after ECMO treatment		
Yes	7	63.6
No	4	36.4

Table 3
Descriptive characteristics of participants' health status and treatment (n = 11).

Descriptive characteristics	n	%
Reasons for ECMO treatment		
Postcardiotomy cardiogenic shock	5	45.4
Graft failure after lung transplantation	2	18.2
Pneumonia	2	18.2
E-CPR	1	9.1
Myocarditis	1	9.1
Vessels used in ECMO treatment		
Femoral vein	11	100
Femoral artery	10	90.9
Subclavian artery	1	9.1
Respiratory maintenance during ECMO		
Intubation	5	45.4
Spontaneous breathing	3	27.3
Tracheostomy	3	27.3
Duration of ECMO treatment (day) ($\bar{X} \pm SS = 8.64 \pm 11.6$; min = 1, max = 43)		
1–10	9	81.8
≥ 11	2	18.2
Complication		
Yes	9	81.8
No	2	18.2
Types of Complications (n = 9)*		
Bleeding	7	77.7
Problems in musculoskeletal system (atrophy, cramp)	7	77.7
Pain	6	66.6
Impaired renal function	5	55.5
Pressure injury	5	55.5
Infection (wound site, systemic)	3	33.3
	$\bar{X} \pm SD$	Min–Max
Intensive care stay (days)	18.7 ± 16.94	5 – 52
Hospital stay (days)	68.09 ± 45.97	21 – 187
Time after discharge (months)	3.864 ± 2.58	1–7

ECMO: Extracorporeal membrane oxygenation, E-CPR: Extracorporeal cardiopulmonary resuscitation.

* Patients reported multiple complications. Percentages were taken over n, n folded.

Table 4
Categories, themes, and subthemes based on participants' experiences.

Category	Theme	Subtheme
Pre-Discharge Period	Physical problems	Limited physical mobility
		Pressure injury
		Pain
	Psychosocial problems	Weight loss
		Feeling cold
		Bleeding
Need of Discharge Education	Infection	
	Anxiety - Fear	
	Sadness	
Post-Discharge Period	Physical problems	Limited physical mobility
		Pain-numbness
		Dependence in self-care
	Psychosocial changes	Lifestyle changes
		Changes in employment status
		Emotion-focused coping
Coping with problems	Problem-oriented coping	
	Expectations of health-care system	

the study addressed problems during hospital stay affecting life following discharge as well.

Pre-discharge period

Theme 1. Physical problems

Limited physical mobility: Seven participants stated that they had to spend long periods of time immobile in bed due to ECMO cannula in the ICU.

...You cannot get up when connected to ECMO, you can even scratch your back, you cannot do anything. You are in bed all day every day. Your legs and whole body go numb after a while... (P5, 26A, M)

I just couldn't move, I felt like a robot... (P9, 38A, F)

Pressure injury: Five participants reported sacral and heel pressure injuries as they had to spend long periods of time immobile in bed. One participant stated that she developed deep pressure injury in the sacral region, and therefore, was treated with vacuum-assisted closure (VAC) therapy.

All you can do is lay in bed, so, I had a hole in my tail end, you could even see the bone through it... (P3, 52A, M)

I had a sore on my back from lying in bed, you could fit a fist in there, it was quite deep, you could even see the bone through it... (P9, 38A, F)

Weight loss: Seven participants who underwent intubation or tracheostomy lost weight because they could not be fed orally or had no appetite. Participants stated that they lost about 10 kg during ECMO.

...You cannot eat when connected to ECMO. I was 75 kg when I was hospitalized, and now I am 64... (P5, 26A, M).

Bleeding: Seven participants reported bleeding in the cannula insertion site due to anticoagulant treatment.

...I had a bleeding at the ECMO insertion site once, and they gave me two stitches. It began bleeding again the day after. You know the nosebleed that you have when you take blood thinners, I had never had such a nosebleed like that before... (P5, 26A, M)

Pain: Six participants reported pain in pressure areas and in cannula insertion sites and during cannula removal at the end of ECMO treatment.

...Once ECMO was started I couldn't get up or turn right or left, so, I had pain on my back... (P5, 26A, M)

...Along the hose and my legs... my crotches were like getting tense... (P9, 38A, F)

Infection: Two participants reported infection at the cannula insertion sites. One of them stated that he was treated with VAC due to cannula entry site infection. The other reported bleeding and then infection in the groin.

I had an ECMO-related infection, which was treated with a VAC (vacuum assisted closure) for 8 days... (P5, 26A, M)

Feeling cold: One participant stated that he felt cold during ECMO. He told the health team that he was cold and stated that he felt it when ECMO temperature was increased.

...I felt very cold one night, I felt like I was freezing. I told the doctor about it. He turned the heat of ECMO up, and I immediately felt warm... (P5, 26A, M)

Theme 2. Psychosocial problems

Anxiety-fear: Three participants expressed concern and fear because of the way the ECMO machine looked and the fact that they were connected to it.

...and I looked at the machine and I thought I was gonna get stuck in it, like it was not gonna let go of me and was gonna kill me (P9, 38A, F)

You feel closer to death; you end up thinking 'am I gonna spend the rest of my life bound to this machine?' (P5, 26A, M)

Sadness: Two participants felt sad because they were away from their families and friends.

...I was so sad when I was thinking about my kids... (P9, 38Y, F)
I was not getting the support I needed, which was also making me sad... (P4, 53A, M)

Theme 3. Need of discharge education

Seven participants stated that they mostly received information on their primary disease. They stated that they needed training on post-discharge ECMO-related complications and home care as well as on primary diseases and surgical complications.

Doctors told me to stay indoors to avoid infection and physiotherapists recommended a program for foot activities. (P5, 26A, M)
They told me to stick to my diet, to eat little, to take my medication and to stay away from cold and the crowd... (P11, 34A, M)

Post-discharge period

Theme 1. Physical problems

Eight participants stated that they had difficulty moving their lower extremities following discharge. Subclavian artery was used on one of the participants and femoral artery-vein was used on the others for cannulation. Participants stated that they had difficulty getting out of bed, walking, climbing stairs and performing activities of daily living independently in the first months after discharge due to femoral artery cannulation and prolonged inactivity.

I could not walk when I got first discharged (P1, 53A, M)
My left leg is not as strong as before. The first three months, I could not sit, except on the toilet seat. It just does not let you remain in the sitting position (P5, 26A, M)

Pain-numbness: Some participants reported pain and numbness in the extremities during the post-discharge period due to atrophy of the extremities, pressure injury and cannula insertion problems during hospital stay.

If I turn to my left at night, I feel pain and wake up immediately (P5, 26A, M).

I felt like the insertion sites and my legs and crotches got tense (P9, 38A, F)

Both my feet used to get numb when I lay down at night. I could not step on my heels. I felt like I was stepping on concrete (P10, 20A, M)

Dependency in self-care: Most participants stated that, due to movement limitations in the first months, they had difficulty meeting self-care needs such as eating, drinking, getting dressed, toileting and bathing, and therefore, they needed help from others.

The first time I was discharged, I could not go to the bathroom. My wife was helping me. I could not even take a shower by myself, so my wife was helping (P1, 53A, M).

I could not shave by myself for more than a month. They helped me take a shower, get dressed and eat... (P6, 61A, M)

Theme 2. Psychosocial changes

Lifestyle changes: Six participants stated that they experienced changes in their daily activities, habits and lifestyles due to ECMO-related physical problems and self-care needs following discharge.

For example, I cannot kneel now. I had to perform prayer sitting (P1, 53A, M)

I cannot swim anymore. I cannot go into the sea or the pool for fear of infection (P5, 26A, M).

I cannot stay in my home anymore because I cannot climb up five floors, so I have to stay with my son (P7, 68A, F).

Changes in employment status: Three participants stated that they had changes in their employment status after discharge. The two stated that stopped working while the other stated that he found a different job that suited his functional capacity.

...I started working for my uncle a month after I was discharged. I do not work hard, I just run errands and wait tables... (P10, 20A, M).

Theme 3. Coping with problems

Emotion-oriented coping mechanisms: Most participants stated that they received family support and/or developed their own sources of motivation to cope with problems. The participants who acknowledged their conditions stated that they had adhered to treatment.

I have an 11-year-old daughter and a wife; I am responsible for them.

I have never been in despair as I draw strength from their presence. (P3, 53A, M)

...I have always motivated myself. I did not shut myself. My family supported me a lot... (P5, 26A, M)

Problem-oriented coping mechanisms: Seven participants stated that they were exercising intensely and regularly to cope with physical problems that they experienced at home.

We got a wheelchair, a walker and an air bed. I did exercise with a therapist three days and with my assistant two days a week. (P7, 68A, F)

...I walked every day and I walked at home at night. I took a thousand steps at night... (P11, 34A, M)

Theme 4. Expectations of the healthcare system

Five participants stated that they had expectations of the healthcare system for the solution of their ECMO-related problems following discharge.

If the hospital had provided more physiotherapy support, I would have been discharged, not in 52 days, but maybe in 32 days. (P3, 53A, M)

...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... (P5, 26A, M)

Quantitative

Table 5 shows the EQ-5D-5 L results. As for mobility, 36.4% of participants had no difficulty, 36.4% had slight difficulty and 18.1% had moderate difficulty in walking. As for self-care, 27.2% of participants stated that they had moderate problems washing or dressing themselves and 45.7% had no problems. Of participants, 45.7% had no difficulty and 18.1% had moderate difficulty performing the usual activities while 18.1% could not perform the usual activities. As for pain and discomfort, 54.3% of participants reported slight pain or discomfort. Of participants, 72.8% did not report anxiety and depression while 18.1% reported slight and 9.1% reported severe anxiety and depression. Participants' mean EQ VAS score was 73.6 ± 16.89 (Table 5).

Table 5
Results of EQ-5D-5L scale.

EQ-5D-5L Subdimensions (n:11)	n	%
Mobility		
I have no problems in walking about	4	36.4
I have slight problems in walking about	4	36.4
I have moderate problems in walking about	2	18.1
I have severe problems in walking about	1	9.1
I am unable to walk about	0	0
Self-Care		
I have no problems washing or dressing myself	5	45.7
I have slight problems washing or dressing myself	2	18.1
I have moderate problems washing or dressing myself	3	27.2
I have severe problems washing or dressing myself	0	0
I am unable to wash or dress myself	1	9.1
Usual Activities		
I have no problems doing my usual activities	5	45.7
I have slight problems doing my usual activities	2	18.1
I have moderate problems doing my usual activities	2	18.1
I have severe problems doing my usual activities	0	0
I am unable to do my usual activities	2	18.1
Pain/ Discomfort		
I have no pain or discomfort	5	45.7
I have slight pain or discomfort	6	54.3
I have moderate pain or discomfort	0	0
I have severe pain or discomfort	0	0
I have extreme pain or discomfort	0	0
Anxiety/Depression		
I am not anxious or depressed	8	72.8
I am slightly anxious or depressed	2	18.1
I am moderately anxious or depressed	0	0
I am severely anxious or depressed	1	9.1
I am extremely anxious or depressed	0	0
EQ-5D-5 L Visual Analogue Scale Score	$\bar{x} \pm SD$	Min / Max
	73.64 ± 16.89	50 / 100

Discussion

During ECMO, participants suffered from limited physical mobility, sacral and heel pressure injuries and pain due to immobility. Patients lie on their backs to prevent cannula displacement and to maintain blood flow during ECMO. In the study, the mean duration of ECMO was 8.64 ± 11.6 days. Therefore, the fact that participants lied on their backs with limited movement during ECMO resulted in pressure injury and pain. Our results are similar to those reported by previous studies.^{27,28} The prevalence of pressure injury among ECMO patients ranges from 13% to 38%.^{27,28} One of our participants developed fourth-degree pressure injury and was treated with VAC. Pressure injury observed in our participants might be due to longer stay in hospital ICU and inability to reposition due to hemodynamic instability and cannula safety. The possibility of advanced-stage pressure injury should be taken into account in patients with prolonged ECMO support and at high risk of pressure injury. Ensuring cannula safety and changing position might prevent pressure wound development in ECMO patients.^{29,30} Care packages including skin assessment and positioning should be used during ECMO support.^{31,32}

The management of physical immobility and pain during ECMO may affect post-discharge problems.¹² Participants reported limitations of mobility in the extremities, difficulty walking and, pain and numbness in the lower extremities in the early post-discharge period. Limited mobility and pain in the first months of discharge prevent patients from performing their own self-care.³³ Most participants had difficulty getting dressed and undressed, and bathing and managing their toilet needs. Some participants had to move in with their children or parents because they could not walk by themselves and could not perform self-care. They also quit their hobbies, had limited social relationships and

family roles and could not return to work. Chen et al.¹² reported weakness in the lower extremities, difficulty moving and squatting on the toilet seat, concern about traveling due to physical limitations, changes in family roles and isolation from social and professional networks in ECMO patients. Combes et al.³⁴ also reported that the social lives of ECMO patients were limited due to physical limitations. In this study, participants used problem-oriented methods in order to cope with physical problems following discharge. They received physiotherapy support, performed daily and walking exercises and used walking aids to solve the post-discharge physical problems directly. Chen et al.¹² reported that patients received physical rehabilitation support, used complementary medicine methods such as acupuncture, and performed weekly exercise programs such as Kung Fu to solve physical problems after ECMO treatment. In order to prevent these post-discharge problems, patients and their families should be provided with discharge education, post-discharge follow-up should be integrated into routine clinical practice, and exercise programs should be developed for those in need.

Zeburh et al.³² reported malnutrition in ECMO patients. In this study, most participants stated that they lost about 10 kg during ECMO support. This problem affected by ECMO as well as other factors such as mechanical ventilation and sedation in ICUs adversely affects post-discharge period and delays recovery. In order to manage this problem and to reduce time on ECMO and in ICUs, nutritional status should be evaluated, the level of malnutrition should be determined, and early enteral or parenteral nutrition support should be initiated within 24–48 h during ECMO treatment.³⁵

In some ECMO cases, patients are kept hypothermic to reduce oxygen consumption and cardiac output during ECMO.³⁶ In this study, one participant stated that he felt cold during ECMO due to therapeutic hypothermia. No similar finding has been reported in the literature. This result indicates that ECMO patients might feel cold during the treatment, and therefore, this should be taken into account in the care of particularly non-sedated patients.

ECMO treatment has psychosocial and physical effects on patients during treatment and after discharge.^{37,38} Tramm et al.⁹ reported depression (13%) and anxiety (9%) in ECMO patients. In this study, participants experienced fear and anxiety thinking that they might have to spend the rest of their lives bound to the ECMO machine and were upset that they were away from their families in ICUs. In another study by Tramm et al. fear, stress, anxiety, paranoia and horror were reported in ECMO patients due to prolonged immobilization, mechanical ventilation, intensive care process, chronic diseases and general condition changes.³⁹ It should be taken into consideration that the ECMO device may cause fear and anxiety in patients and, therefore ECMO patients should be evaluated and supported psychosocially during and after the treatment. In the study, participants used emotion-focused methods and found sources of motivation such as receiving family support and remembering their responsibilities in order to cope with psychosocial problems following discharge. Monitoring patients at home after discharge, assessing physical and psychosocial conditions, identifying solutions together with patients and their families and creating social support groups can help patients cope with problems after ECMO treatment.⁴⁰

According to ELSO guidelines, ECMO patients should be provided with discharge education rather than just being informed in order to prevent post-discharge problems and to improve their quality of life. In this respect, a comprehensive and individual discharge education program under the leadership of ECMO nurses can solve and manage post-discharge problems. Most of our participants stated that they were informed on discharge, which was mostly based on primary disease and surgery. They also stated that they expected the healthcare system to provide them with comprehensive discharge education and to implement physical exercise programs during hospital stay and at discharge. The results show that the

discharge education program should contain regular exercises to increase physical functions and information on adequate nutrition, wound care and self-care, coping with pain and adapting to psychosocial changes. Providing ECMO patients with education for hospital stay and discharge and supporting them in coping with problems improve their health.¹²

In this study, quality of life was determined using the EQ-5D-5 L scale. The results showed that most participants had slight and moderate difficulty in mobility and usual activities. Participants also stated that they had slight pain/discomfort after discharge. The quality of life scale results were consistent with the interview results and, similar to previous studies.^{41,37} The studies reported ECMO patients had slight or moderate problems with mobility, usual activities and pain/discomfort following discharge.^{41,37} Orbo et al.⁴¹ reported 90% of the ECMO patients had no problems with self-care. In our study, half of the participants had slight and moderate problems with self-care due to difficulty in mobility. Hodgson et al.³⁷ reported severe/extreme anxiety and depression in 38% of ECMO patients after discharge. In our study results, 9.1% of participants had severe anxiety and depression. Participants' EQ-VAS scores also supported the interview data. Participants had high perceptions of their health according to the EQ-VAS. Studies on the quality of life of ECMO patients have reported similar results.^{11,42} Galazzi et al.¹¹ used a similar research instrument and reported that discharged ECMO patients had a health perception of 75%. Although some of our participants had some problems after discharge, they had high perceptions of their health.

Conclusion

To our knowledge, this is the first mixed-methods study to provide detailed information on ECMO patients' post-discharge experiences and quality of life. This study is important in that it helps us understand patients' experiences of during ECMO treatment and post-discharge needs. The results show that although ECMO patients suffer from some post-discharge problems, they have high perceptions of their quality of life. To prevent ECMO patients' problems following discharge and to improve their quality of life; (1) more activity and exercise programs during ECMO treatment should be offered to ECMO patients to prevent pre- and post-discharge problems related to limited physical mobility, (2) they should be provided with structured discharge education and (3) followed up at home after discharge, (4) home care services should be made accessible to them and (5) social support systems should be developed to help them cope with physical and psychosocial changes following discharge.

Limitations

The participants had long ICU stays in the study. The experiences such as infection, weight loss and psychosocial problems during ECMO in intensive care unit might have been affected by treatments or critical illness. The study had small sample size and the center specific findings of the study could not be generalizable.

Declaration of Competing Interest

All listed authors meet the authorship criteria and that all authors are in agreement with the content of the manuscript.

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