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Coping strategies, anxiety and depressive symptoms in family members of patients treated with extracorporeal membrane oxygenation: A prospective cohort study



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ABSTRACT

Background: Family members of patients treated with Extracorporeal Membrane Oxygenation (ECMO) during an Intensive Care Unit (ICU) stay are at risk of developing symptoms of anxiety, depression and Post-Traumatic Stress Disorder (PTSD). Coping strategies used by family members may play an important role in the severity of some of these symptoms.

Objectives: The primary aim of this study was to describe coping strategies used by family members of ECMO-treated patients during ICU admission and recovery period. The secondary aim was to explore the course of the symptoms anxiety, depression, PTSD, and Health Related Quality Of Life (HRQOL) over time.

Methods: In this single-center prospective longitudinal study, validated questionnaires were used to measure coping strategies, symptoms of anxiety, depression and PTSD, and HRQOL in family members of ECMO-treated patients directly after the start of ECMO and at one and six months after the start of ECMO.

Results: Family members ($n = 26$) mainly used problem-focused coping strategies. Symptoms of anxiety appeared to be most present during treatment but decreased over time, as did symptoms of depression and PTSD. HRQOL was severely affected, especially in the mental domain, and did not improve over time.

Conclusion: In family members of ECMO-treated patients, problem-focused coping mechanisms were most prominent. Psychological functioning was impaired on admission but improved over time, although a mild reaction to stress remained.

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Introduction

Extracorporeal Membrane Oxygenation (ECMO) is an advanced, highly technical treatment used in the Intensive Care Unit (ICU). It temporarily supports the heart and/or lung function of critically ill patients when conventional treatments have failed. ECMO treatment is usually unexpected and acute after the development of respiratory failure, cardiogenic shock or cardiac arrest.

Abbreviations: ECMO, Extracorporeal Membrane Oxygenation; HRQOL, Health Related Quality Of Life; IABP, Intra-aortic Balloon Pump; ICU, Intensive Care Unit; LOS, Length Of Stay; PICS-F, Post-Intensive Care Syndrome-Family; PTSD, Post-Traumatic Stress Disorder; VAD, Ventricular Assist Device

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A patient's acute and unexpected admission to an ICU can have a negative impact on family members and can trigger stress and emotions. The Post Intensive Care Syndrome-Family (PICS-F) comprises symptoms of anxiety, depression and Post-Traumatic Stress Disorder (PTSD) in relatives of critically ill patients.^{1,2} A review on the perceived burden in informal caregivers of ICU survivors reported symptoms of anxiety (15–24%), depression (5–36%) and PTSD (35–57%) and a major decrease in Health-Related Quality of Life (HRQOL) after six months. Furthermore, up to 50% of surveyed family members reduced their working hours, resigned to provide informal care or were fired as a result of focusing on providing such care.³

Factors associated with a higher prevalence and severity of PICS-F symptoms include the severity of patient's illness, patient's death, family member being female, family member being a child of the patient, family members being concerned with decision-making and family members' psychological history.^{4–8} Since ECMO treatment is

often a last resort and life-saving option with a high mortality rate, family members of ECMO-treated patients seem to be at risk of developing PICS-F. In addition, patients treated with ECMO are generally deeply sedated, making verbal contact impossible.

Coping strategies play an important role in overall physical and psychological health outcomes and can be a predictor of the severity of PTSD.^{9,10} Several authors assume that coping is a predisposition that reflects a person's tendency to respond to stressful events in a certain way across time and circumstances.^{11,12} Coping behaviors and mechanisms can be divided into three overarching coping strategies: problem-focused, emotion-focused and avoidant coping.¹³

Several studies have identified the need for family members to receive more information and reassurance during a patient's ICU stay. Furthermore, studies describe the negative impact on family members' psychological health and well-being when their perceived needs are not met by healthcare professionals.^{14,15} Research into the relationship between coping strategies and the severity of PICS-F is lacking regarding family members of ECMO patients. More knowledge is needed concerning the course of symptoms and prognostic factors for PICS-F in family members of ECMO patients; such knowledge could be used to improve strategies for supporting family members at risk of PICS-F.

The primary aim of this study was to describe coping strategies used by family members of ECMO-treated patients during ICU admission, ICU stay and the subsequent recovery period. The secondary aim was to explore the course of the symptoms anxiety, depression and PTSD and HRQOL over time.

Methods

Design and sample

A single-center prospective longitudinal study was conducted with a descriptive design involving family members of ECMO patients admitted to the ICU of the University Medical Center Groningen in

the Netherlands. Family members of all ECMO patients admitted to the ICU between January 2019 and March 2020 were asked to participate in the study within five days after the start of ECMO treatment. Family members were defined as partners, siblings, parents and children. Several family members could participate per patient. Exclusion criteria were aged under 18 years or unable to read or understand Dutch.

Ethical considerations

The study was approved by the institutional review board of the University Medical Center Groningen (UMCG, METc 2018/699) and conducted in agreement with the principles of the Declaration of Helsinki. Written informed consent was obtained from all participants.

Procedure

During the inclusion period, families were approached by one of the trained research nurses, who provided information about the study and asked for their consent. When one or more family members were willing to participate, the first questionnaire was immediately provided and completed as soon as possible. The research nurses collected the questionnaire, including address details, when it was completed. Follow-up questionnaires were sent to each participant's home address at one and six months after the start of ECMO treatment. Fig. 1 provides an overview of the study and data collection.

Outcome measures

Coping strategies were measured with the Brief COPE Inventory,¹⁶ a 28-item self-report questionnaire designed to determine a person's primary coping strategy. Items are scored using a four-point Likert scale, with responses ranging from 1 ("I have not been doing this at all") to 4 ("I have been doing this a lot"). Higher scores indicate

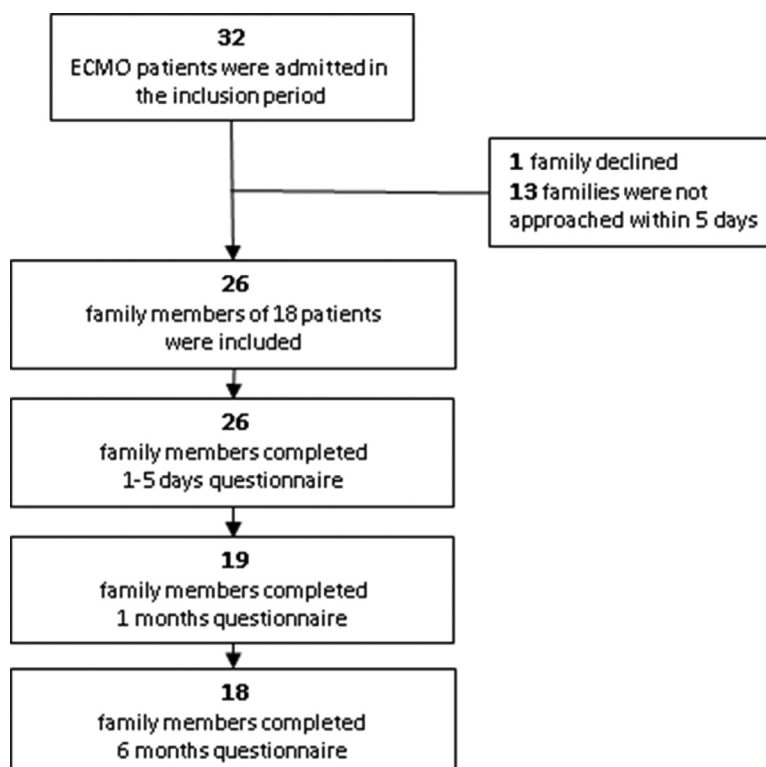


Fig. 1. Flowchart of the study

greater use of the specific type of coping. The Brief COPE has been validated in patients with burn injuries¹⁷ and athletes¹⁸ and was divided into three factors (problem-focused, emotion-focused and avoidant coping strategies) in 2012.¹²

Psychological functioning (i.e. symptoms of anxiety and depression) was measured by the Hospital Anxiety Depression Scale (HADS).¹⁹ The HADS consists of two subscales that evaluate symptoms of depression and symptoms of anxiety. Both subscales contain seven items with a four-point Likert scale for each question. The total scores per subscale range from 0 to 21, with the sums categorized as normal (0–7), mild (8–10), moderate (11–14) and severe (15–21). The validity of the HADS was confirmed in a literature review,²⁰ with Cronbach's alpha varying from 0.68 to 0.93 for the HADS anxiety scale and from 0.67 to 0.90 for the HADS depression scale.

Symptoms of PTSD were measured by the Dutch version of the Impact of Event Scale (IES).^{21,22} The IES is a self-report questionnaire for measuring reactions to traumatic events. It provides information on both the presence and severity of stress-related symptoms and contains 15 questions, each of which is answered as follows: “not at all” = 0, “a little bit” = 1, “quite a bit” = 3 and “extremely” = 5. A sum-score relating to two PTSD dimensions – reliving the experience and avoiding unpleasant feelings or memories of the experience – should be computed, where higher scores indicate more presence of stress-related symptoms. The Dutch version was confirmed to be a valid instrument that provides a reliable impression of the degree of reliving and the degree of avoidance after shocking experiences, with the total Cronbach's alpha being 0.95, while the Cronbach's alpha for the reliving scale was 0.93 and for the avoidance scale 0.90.²²

HRQOL was measured by the Short Form-12 (SF-12) questionnaire, Version 1.²³ The SF-12 is a shortened version of the SF-36 that includes eight questions to be answered on a three-to-five-point Likert scale and four questions to be answered with yes or no. The SF-12 reports two summary scores: a mental component score (MCS-12) and a physical component score (PCS-12). The scores can be reported as z-scores (the difference compared to the population average, measured in standard deviations). Scores range between 0 and 100, and threshold scores in the Dutch population are 50.66 on the PCS-12 and 50.45 on the MCS-12.²⁴

Demographics

Demographic characteristics of family members, such as age, gender, education, occupation, relationship with the patient, pre-existing anxiety and depression, and medication use, were collected in the first questionnaire.

Following confirmation that no objection to the use of data existed, demographic characteristics of the patients, such as age,

gender, days on ECMO treatment, veno-venous-ECMO (supporting lung function only) or veno-arterial-ECMO (supporting both heart and lung function), ICU length of stay, hospital length of stay, mortality at one and six months, ventilation days and reason for ICU admission, were collected from the Electronic Patient File and the community database and were used pseudonymized.

Analysis

The data were analysed using IBM SPSS Statistics 23. For the initial analysis of the SF-12 questionnaire, SAS 9.4 was used. Descriptive data are presented in numbers and percentages, and continuous variables are reported as medians with interquartile ranges (IQR) because of the skewed distribution of the data. Categorical data are presented in proportions. Missing data were handled according to the manual of the respective questionnaires.

Results

Response

Of 18 patients, 26 family members gave informed consent to participate in the study. Of 11 patients, 18 (69.2%) family members provided data for all study time points and completed the study (Fig. 2). Family members of five patients were deemed unable to receive or understand study information during the inclusion period, and family members of eight patients dropped out due to logistical reasons. Family members of one patient declined because they felt emotionally unable to participate.

Study population

Most participating family members were spouses (50%). The median age of the family members was 47 (IQR 18), while the median age of patients was 62 (IQR 18). Five family members (19.2%) had a history of anxiety or depression, but none of them used medication for these conditions. The median duration of the patients' ECMO treatment was 4.5 days (IQR 3.75), and the median ICU length of stay was 17 days (IQR 26.50). Nine (50%) patients received ECMO treatment after a heart or lung transplant. The demographic characteristics of family members and patients are summarized in Table 1A and 1B, respectively.

Coping strategies

Most of the participants primarily used problem-focused coping mechanisms, either on admission as one month after the start of

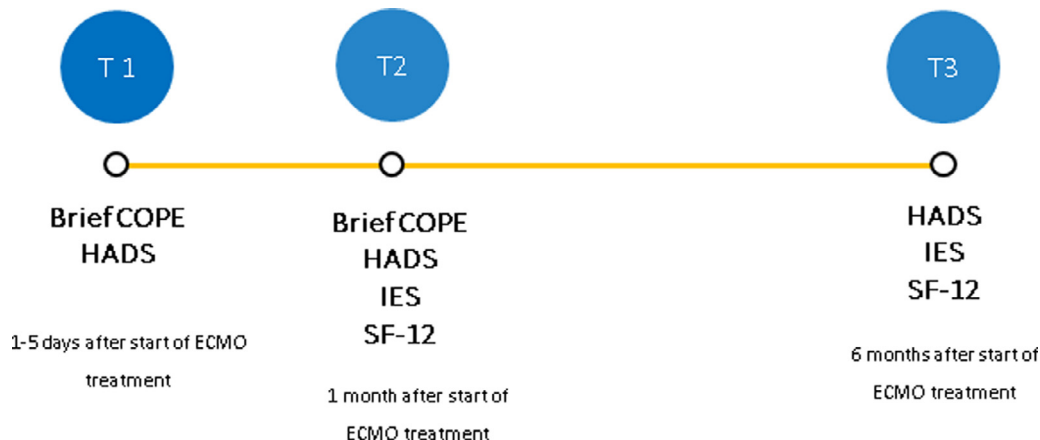


Fig. 2. Overview questionnaires.

Table 1.
A. Baseline characteristics of family members of ECMO patients. B. Baseline characteristics of ECMO patients.

Variable	Family n = 26
Age, years, median (IQR)	47 (18)
Sex, n (%)	
Male	12 (46.2)
Female	14 (53.8)
Relationship to patient, n (%)	
Partner	13 (50)
Child	11 (42.3)
Parent	2 (7.7)
Educational level ¹ , n (%)	
Low	4 (15.4)
Middle	18 (69.2)
High	4 (15.4)
Employed, n (%)	
Yes	20 (79.92)
no	5 (19.23)
missing	1 (3.85)
History of anxiety or depression, n (%)	
yes	5 (19.2)
no	21 (80.8)
missing	0
Use of medication for anxiety or depression, n (%)	
yes	0
no	24 (92.3)
missing	2 (7.7)
Variable	Patient n = 18
Age, years, median (IQR)	62 (18)
Sex, n (%)	
male	8 (44.4)
female	10 (55.6)
ICU admission, n (%)	
Heart or lung transplant	9 (50)
Post cardio-surgical	3 (16.67)
ECPR	2 (11.1)
Severe respiratory failure	4 (22.2)
VV ECMO, n (%)	7 (38.9)
VA ECMO, n (%)	11 (61.1)
Duration ECMO, days, median (IQR)	4.5 (3.75)
ICU LOS, days, median (IQR)	17 (26.50)
Hospital LOS, days, median (IQR)	30.23 (64.72)
Alive after 1 month, n (%)	14 (77.8)
Alive after 6 months, n (%)	13 (72.2)

¹ Educational level classification based on ISCED2011

Abbreviations: ECPR = ECMO Cardio Pulmonary Resuscitation; ICU = Intensive Care Unit; LOS = Length Of Stay; VV = veno-venous; VA = veno-arterial.

ECMO treatment, reflected by total median scores of 2.63 (IQR 1.0) and 2.50 (IQR 0.50), respectively. The mechanisms that were most used were 'positive reframing' and 'acceptance', with median scores for both being 3.0 on admission as well as after one month. Religion was hardly used as a coping mechanism. Participants tended to use several coping strategies simultaneously. The coping mechanisms and strategies used are summarized in Table 2.

Symptoms of anxiety, depression and PTSD

Symptoms of anxiety were most prominent, reflected by median scores of 13 (IQR 6) on admission, 8 (IQR 5) at one month and 6 (IQR 5) at six months, whereas symptoms of depression were reflected by median scores of 10 (IQR 4), 6.5 (IQR 6) and 6 (IQR 6), respectively. Overall, symptoms of anxiety and depression both decreased over time.

Stress-related symptoms such as avoiding similar situations and reliving the event were present at one month but were reduced at six months. After one month, the median total score on the IES was 30 (IQR 27.5), indicating a substantial response to stress, whereas the total median score after six months decreased to 19 (IQR 20), still indicating a mild reaction.

Table 2.
Coping strategies and mechanisms of family members at ICU admission, and 1 month after ICU admission.

Coping strategy	Coping mechanism	Admission	1 month
Problem-focused (range 1–4)	Active coping	2.5 (1.0)	2.5 (0.50)
	Use of informational support	2.0 (1.0)	2.0 (1.0)
	Positive reframing	3.0 (1.0)	3.0 (0.50)
	Planning	3.0 (1.0)	2.5 (1.0)
	Total	2.63 (1.0)	2.50 (0.50)
Emotion-focused (range 1–4)	Emotional support	2.0 (1.0)	2.0 (0.00)
	Venting	2.0 (1.0)	2.0 (1.0)
	humor	2.0 (1.0)	2.0 (1.0)
	Acceptance	3.0 (1.0)	3.0 (1.0)
	Religion	1.0 (0.50)	1.0 (0.00)
	Self-blame	1.0 (1.0)	1.0 (1.0)
	Total	1.83 (0.58)	1.92 (0.42)
Avoidant (range 1–4)	Self-distraction	2.5 (1.0)	2.5 (1.5)
	Denial	1.0 (0.50)	1.0 (0.00)
	Substance use	1.0 (0.00)	1.0 (0.50)
	Behavioral disengagement	1.0 (0.50)	1.0 (0.00)
	Total	1.50 (0.25)	1.50 (0.50)

All numbers given are the median and interquartile ranges (IQR).

Table 3.
Psychological functioning of family members at ICU admission, and 1- and 6 months after ICU admission.

Questionnaire	Scale	Admission	1 month	6 months
HADS	Anxiety (range 0–21)	13.0 (6)	8.0 (5)	6.0 (5)
	Depression (range 0–21)	10.0 (4)	6.5 (6)	6.0 (6)
IES	Reliving (range 0–35)	–	18.0 (16)	8.0 (17)
	Avoiding (range 0–40)	–	15.0 (13)	6.0 (10)
	Total (range 0–75)	–	30.0 (27.5)	19.0 (20)
SF-12	Physical Component Scale (range 0–100)	–	49.96 (15.0)	51.36 (11.97)
	Mental Component Scale (range 0–100)	–	38.85 (7.0)	38.90 (6.3)

All numbers given are the median and interquartile ranges (IQR).

Health-related quality of life

Median scores at the SF-12 questionnaire were 49.96 (IQR 15.0) at the PCS-12 and 38.85 (IQR 7.0) at the MCS-12 after one month. The PCS-12 score increased after six months to a median score of 51.36 (IQR 11.97), whereas the MSC-12 score remained virtually the same, with a median score of 38.90 (IQR 6.3). Table 3 summarizes the scores on the HADS, IES and SF-12 questionnaires.

Discussion

To our knowledge, this study is the first to describe coping strategies used by family members of patients receiving ECMO treatment during ICU admission and at one month after ECMO treatment. Furthermore, this study explored the course of symptoms of anxiety, depression, PTSD and HRQOL in family members over time up to six months after ECMO treatment. We found that problem-focused coping was the primary coping strategy used by family members. In addition, symptoms of anxiety and depression were present but decreased over time. Furthermore, a mild stress reaction was persistent up to six months post ECMO treatment. HRQOL was affected up to six months, especially in the mental domain.

The way family members are coping with a critically ill relative being an ICU patient is a predictor of the severity of PTSD.¹³ Avoidance coping has the strongest association with PTSD symptoms,^{9,10,25} although it can reduce stress when nothing can be done to address the problem.²⁶ As this is the case in family members of patients

receiving ECMO treatment, one could argue that using some avoidant coping mechanisms may be expedient in this situation. Nevertheless, in our study, family members used fewer avoidant coping mechanisms than problem-focused coping mechanisms. This may explain the improving scores on the HADS and IES over time and confirm the outcomes of other studies.^{9,10,25} In addition, certain coping characteristics, such as optimism, resilience and social support, are associated with less psychological distress in family members of mechanical ventilation survivors.²⁷ These characteristics can be seen as active ways of coping that are classified under problem-focused coping.

The number of small studies on ECMO-treated patients is increasing, because the treatment is scarcely used. To increase sample size, future research on this topic might consider the possibility to include patient groups with similar devices. ECMO can be seen as an extremely intensive treatment, and the impact of such treatment might be comparable to treatment with Left Ventricular Assist Devices (LVAD) or Intra-aortic Balloon Pumps (IABP). A study conducted in LVAD patients and their partners²⁸ showed a partner response comparable to family members in our study, with decreasing symptoms of anxiety over time. Also, research in family members of the general ICU population is certainly present, showing family members in our study responding similarly to family members of other critically ill patient groups.^{1–8} A study performed in 2020 concerning coping strategies of family members of patients on prolonged mechanical ventilation, found the use of various coping strategies²⁹ and a review on coping strategies by family members of critically ill patients reported a higher use of problem-focused coping.³⁰

A relevant variable with regard to the improvement of outcomes of psychological functioning over time might be the disease history of the patient. Nine patients in our study received ECMO treatment after a heart or lung transplant, indicating a longer period of serious health issues and impairment prior to the ICU admission. It is likely that the quality of life of these patients has improved after transplant, which may have a direct impact on the psychological well-being of family members. This is in line with other findings. In a study performed in 2014 involving relatives of lung or heart transplanted patients,³¹ family members experienced great relief after the transplantation, allowing themselves to think about the future again. In addition, Tramm et al.³² identified similar experiences in a qualitative interview study in relatives of ECMO-treated patients. All family members of Ventricular Assist Device (VAD) implanted patients claimed that the implantation had fundamentally improved their situation when compared to their life before the implantation, despite the experiences they had in the ICU. In 2020, van Sleuwen et al.³³ found in their interview study that family members were overburdened as informal caregivers of their chronically ill relatives prior to hospitalization. Family members in this study stated that the ICU stay offered them more time and space for themselves.

Although we found improvement in depression, anxiety and stress in our study, family members experienced a severely reduced HRQOL, especially in the mental domain, despite not being sick themselves. The family members reported MCS-12 scores below average compared to the Dutch population,²⁴ and the scores remain below average after six months.

Healthcare professionals should be more aware of persistent low HRQOL scores in family members. In addition, according to Nadig et al.,²⁷ screening for unmet social needs might be a strategy to support family members. In their study, they found better social support to be associated with lower rates of anxiety, depression and PTSD. They explored coping as a multi-faceted construct rather than a stand-alone strategy. In addition, Cox et al.³⁴ developed a telephone-based coping skills training intervention for acute lung injury survivors and their caregivers to reduce psychological stress and found this intervention to be feasible even though participants used multiple ways of coping. Furthermore, family members in the Tramm study²⁶ recommended several supportive strategies for healthcare

providers to use (e.g. peer support, close communication and being aware of the variety of roles family members perform, causing stress and strain). In another qualitative study where experiences of ECMO survivors themselves were explored,³⁵ the role of family members was found to be of major importance to patients in terms of support. Family members were also the main source of information for the patients, as the former relayed everything that had happened to the patients. From this perspective, it is also greatly important for ECMO patients that their family members receive appropriate support.

Despite the fact that family members in our study mainly used effective coping strategies, we recommend screening for coping strategies to support family members during an ICU stay. In addition, to enable family-centered care, we advise screening for other influencing factors (e.g. social support) as well.

Strengths and limitations

This study used validated questionnaires and contributed to the small body of literature on coping strategies and follow-up in family members of patients who received ECMO treatment. Furthermore, ECMO is a relatively new treatment option that is scarcely used, resulting in a small patient population. Therefore, the cohort of 26 family members can be seen as a representative reflection of the patient population visiting the ICU of our university hospital. Moreover, the response rate was relatively high, which strengthens the longitudinal findings.

We acknowledge several limitations. First, we only describe findings from one university hospital in the Netherlands where ECMO treatment is performed, which limits the generalizability of our findings. Second, the sample size could have been larger had we not had to end the recruitment period prematurely due to the COVID-19 pandemic. Third, we did not differentiate between reasons for ECMO treatment at inclusion; consequently, the patients' disease history, although appearing to be relevant, could not be adequately accounted for.

Conclusion

In family members of ECMO-treated patients, problem-focused coping mechanisms were most prominent. Symptoms of anxiety, depression and PTSD were present on admission but improved over time, although a mild reaction to stress remained. HRQOL was severely impaired over time, mainly in the mental domain. Family members of ECMO-treated patients might benefit from supportive interventions during an ICU stay and the recovery period to enable them using effective coping strategies.

Declaration of Competing Interest

The authors state there are no competing declarations of interest. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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