



EARLY GUIDED PALLIATIVE CARE COMMUNICATION FOR PATIENTS WITH COVID-19 RECEIVING ECMO

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Background Extracorporeal membrane oxygenation (ECMO) combined with COVID-19 presents challenges (eg, isolation, anticipatory grief) for patients and families.

Objective To (1) describe characteristics and outcomes of patients with COVID-19 receiving ECMO, (2) develop a practice improvement strategy to implement early, semistructured palliative care communication in ECMO acknowledgment meetings with patients' families, and (3) examine family members' experiences as recorded in clinicians' notes during these meetings.

Methods Descriptive observation of guided, in-depth meetings with families of patients with COVID-19 receiving ECMO, as gathered from the electronic medical record of a large urban academic medical center. Most meetings were held within 3 days of initiation of ECMO.

Results Forty-three patients received ECMO between March and October 2020. The mean patient age was 44 years; 63% of patients were Hispanic/Latino, 19% were Black, and 7% were White. Documentation of the ECMO acknowledgment meeting was completed for 60% of patients. Fifty-six percent of patients survived to hospital discharge. Family discussions revealed 7 common themes: hope, reliance on faith, multiple family members with COVID-19, helping children adjust to a new normal, visitation restrictions, gratitude for clinicians and care, and end-of-life discussions.

Conclusion Early and ongoing provision of palliative care is feasible and useful for highlighting a range of experiences related to COVID-19. Palliative care is also useful for educating patients and families on the benefits and limitations of ECMO therapy. (*American Journal of Critical Care*. 2023;32:166-174)

CE 1.0 Hour

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Extracorporeal membrane oxygenation (ECMO) is used as a bridge to recovery in patients with acute reversible conditions, to transplantation in patients with irreversible cardiac or respiratory failure, and to ventricular assist device therapy in some patients with cardiac failure.¹ The World Health Organization has recommended considering the use of ECMO for patients with COVID-19 hypoxemia refractory to mechanical ventilatory support.^{2,3}

Early publications showed a high mortality rate in patients with COVID-19 receiving ECMO, initially leading clinicians to recommend withholding ECMO support in patients with COVID-19.^{4,5} Further studies demonstrated favorable survival outcomes in patients with COVID-19 cared for at sites with significant ECMO experience; however, in all studies, the vast majority of patients who survived hospitalization had significant functional disability.^{6,7} Given the critical frailty of patients who require the complex support that ECMO provides,⁸ realistically managing families' expectations for potential recovery can be difficult. This difficulty increases as time passes for patients receiving ECMO whose clinical status fails to improve.

Palliative care is an interdisciplinary team-based specialty that supports seriously ill patients and their families with high-level communication and symptom management skills to address physical, emotional, and existential suffering.^{9,10} Studies

have shown that palliative care consultation improves the quality and quantity of communication with family members.^{11,12}

Society- and government-sponsored guidelines from around the world support palliative engagement in the care of patients with COVID-19.¹³⁻¹⁵ Palliative care specialists possess the necessary communication skills to address the unique needs of patients and their family members experiencing the effects of COVID-19.¹⁵⁻¹⁸

Current studies of palliative care for patients receiving ECMO have focused on aspects of end-of-life care, withdrawal of ECMO, and impact on resource use. However, the effect of early, scripted palliative care intervention on the care of patients with COVID-19 receiving ECMO has not been explored.^{19,20} Concerned with high mortality rates and social isolation of vulnerable patients during the pandemic, our critical care and palliative care teams discussed the need for palliative support within 48 hours of cannulation for any hospitalized patient receiving ECMO. For each patient, the specific request (symptom management, goals-of-care conversation to align treatment plans with preference of care, psychosocial-spiritual support to patient and family, etc) was determined collaboratively. The interdisciplinary palliative care consultation included medical, psychosocial, chaplain, and pharmacy assessments. By established protocol, the critical care team notified the palliative care team when patients received ECMO cannulation. We developed a practice improvement strategy that focused on clear communication, guided by a script, between primary clinicians and family members with the support of the palliative care team. This approach could enhance the quality of patient and family care and affect outcomes. The objectives of this study were to (1) describe the characteristics and outcomes of patients with COVID-19 receiving ECMO; (2) develop a practice improvement strategy to implement an early, semistructured palliative care communication

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intervention (ECMO acknowledgment meetings) involving palliative care specialists; and (3) examine family members' experiences recorded in clinicians' notes from these meetings.

Methods

Data Source, Population, and Setting

This work was conducted at a single academic medical center, with data on the patient cohort obtained from an institutional review board–approved ECMO data warehouse. Data managers received detailed instructions and definitions to guide data entry. Accuracy was augmented as needed with manual medical record review, including error and validity checks that

ensured all mandatory fields were completed. This analysis of clinical records was determined to be exempt from review by the institutional review board of the University of Maryland School of Medicine.

Patients aged 18 years or older with COVID-19 who were supported by ECMO between March and October 2020 were included in the cohort.

All patients included in this study received care in the Lung Rescue Unit at the University of Maryland Medical Center in Baltimore, Maryland.

Study Design

This study was a descriptive content analysis of guided in-depth meetings with families of patients with COVID-19 receiving ECMO, as gathered from the electronic medical record. Palliative care specialists sought to promote clear communication between critical care clinicians and patients' family members by providing a specially developed script for initial family meetings in which ECMO therapy was to be discussed. Data were collected from medical record documentation of semistructured interviews and were analyzed using framework analysis.

The palliative medicine team consisted of trained physicians, nurses, nurse practitioners, social workers, pharmacists, and chaplains. Child life specialists were included in family meetings. The ECMO and critical care team consisted of critical care physicians and advanced practice intensivists.

Given the high complexity of the patients' conditions and the number of interdisciplinary clinicians,

uniform verbal and written messages were developed to promote clear communication between clinicians and families and to reduce the risk of miscommunication. Clinicians from palliative care, critical care, surgery, nursing, and social work departments participated in a 2-hour simulation workshop that included role playing of various theoretical scenarios, enabling clinicians to practice a tailored script (see Supplemental Table, available online only at ajconline.org). The script was designed to promote consistent communication and ongoing patient-family engagement in medical decision-making.

Specific hospital protocols were developed such that an interdisciplinary ECMO acknowledgment meeting with family members was planned within 48 to 72 hours of ECMO initiation. These meetings were designed to assess family members' understanding of the complex nature of the ECMO procedure and their emotional state through the use of open-ended questions, active listening, and supportive counseling.

However, participation in family meetings was threatened by strict visitation restrictions during the COVID-19 pandemic. Telehealth video technology was used to replicate the in-person family meeting experience as best as possible. Family meetings sought to explore a patient's goals and values and use shared decision-making to make care recommendations. Families were allowed to express emotions and, when appropriate, receive education on legacy activities to facilitate a patient's narrative life review. Clinicians repeatedly affirmed nonabandonment throughout the entire course of ECMO care.

Subsequent conversations with families focused on building trust and maintaining realistic hope. When guided by the intensive care team, palliative care teams facilitated discussions regarding discontinuation of ECMO when no clinical benefit was being observed in order to reduce harm and further suffering of patients.

Family members' quotes, as described in clinician documentation in the medical record, were analyzed by 2 independent investigators using software-assisted line-by-line coding to identify emerging themes with interrater reliability. Other outcomes measured included the timing and documentation of ECMO acknowledgment meetings, the number of documented in-person and physical family visits, hospital length of stay, and discharge disposition.

Results

Patient demographic and clinical characteristics are reported in Table 1. The study included 43 patients

To promote clear communication between critical care clinicians and patients' family members, a script was developed for initial family meetings in which ECMO therapy was to be discussed.

with a median age of 44 years (range, 37-53 years). Most patients were male (81%) and most were Hispanic/Latino (63%), followed by Black, other races, and White. Most patients had at least 1 comorbidity, including obesity, diabetes mellitus, hypertension, lung disease, and chronic kidney disease.

An ECMO acknowledgment meeting was documented by palliative care staff members for 26 of 43 patients (60%). Among these 26 patients, meetings took place within 3 days of ECMO cannulation for 19 (73%); most meetings (11 [42%]) occurred within 1 day of cannulation (see Figure).Owing to the volume of patient care needed and competing demands on health care workers' time during the COVID-19 pandemic, meetings occurred later than 3 days after cannulation for 7 patients (27%).

Twenty-four of 43 patients (56%) survived to be discharged. Seventeen of 43 (40%) went to an acute care or rehabilitation facility, and 7 of 43 (16%) were able to return home.

The mean hospital stay was 44.9 days (range, 2-125 days). The mean intensive care unit stay was 41.3 days (range, 2-125 days). There was no significant difference in hospital survival or length of stay between patients with and without documented palliative care (ie, an ECMO acknowledgment meeting) (intensive care unit stay, 43.9 days vs 36 days, respectively; $P = .76$ by t test).

Analysis of clinicians' notes uncovered the following themes in family members' comments: (1) hope, (2) reliance on faith and spirituality, (3) multiple family members with COVID, (4) families with young children coping with a new normal, (5) visitation restrictions, (6) gratitude for clinicians and care, and (7) end-of-life discussions (Table 2). Most of the 43 patients used ancillary resources, including social workers (42 [98%]), pastoral care (40 [93%]), and child life specialists (4 [9%]). An ethics committee consultation was provided for 3 patients (7%). All patients' family members had at least 1 documented telehealth video visit, with a mean of 5 video visits per patient. Seven patients (16%) had family members visit in person when cleared by infection prevention staff. Of 19 patients (44%) who died during hospitalization, 6 (32%) had family members present on video calls, and 2 (11%) had family members visit in person.

Discussion

Although born out of the practice of hospice and end-of-life care, palliative care has expanded to providing care for patients at all stages of chronic illness. The American Thoracic Society's clinical policy

Table 1
Demographic characteristics of 43 patients included in the study

| Characteristic | No. (%) |
|------------------------|---------|
| Sex | |
| Male | 35 (81) |
| Female | 8 (19) |
| Race/ethnicity | |
| Hispanic/Latino | 27 (63) |
| Black | 8 (19) |
| Other | 5 (12) |
| White | 3 (7) |
| Comorbidities | |
| Obesity (BMI > 30) | 28 (65) |
| Diabetes mellitus | 11 (26) |
| Hypertension | 8 (19) |
| Overweight (BMI > 25) | 6 (14) |
| Lung disease | 4 (9) |
| Chronic kidney disease | 1 (2) |

Abbreviation: BMI, body mass index, calculated as weight in kilograms divided by height in meters squared.

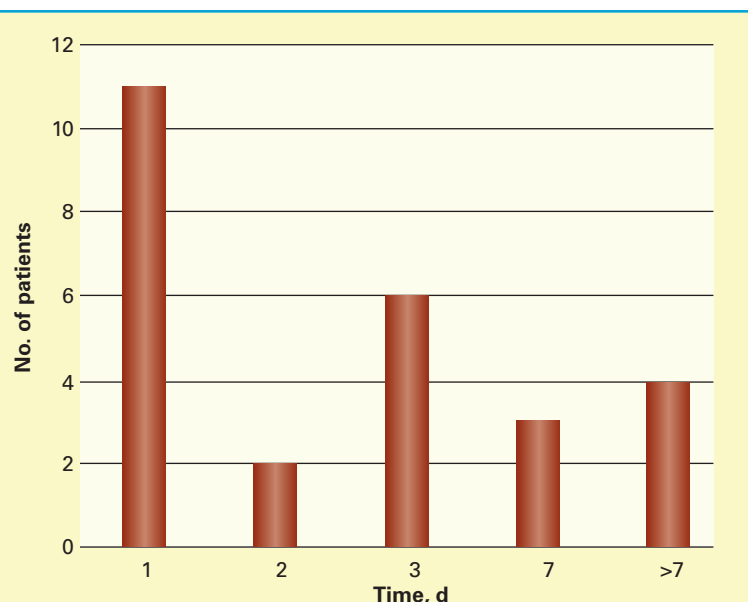


Figure Time elapsed between cannulation and extracorporeal membrane oxygenation acknowledgment meeting with patients' families.

statement supports palliative care specialist involvement in the care of patients with respiratory diseases and critical illnesses with the aims of (1) relieving suffering by managing symptoms to improve quality of life and (2) helping patients define goals of care and make major treatment decisions.^{21,22} Palliative medicine specialists are also helpful in mediating especially challenging care discussions, including navigating family conflict and indecision.²³⁻²⁵

Our study demonstrates that early and ongoing involvement of a palliative care specialist helps patients

Table 2
Thematic grouping of family member quotes
in the medical record

| Theme | Sample quotes |
|---|--|
| 1. Hope | <p>1A Two days after cannulation for ECMO, a patient's father shared that he and patient's mother were "pretty much okay." They were waiting for "good news."</p> <p>1B A patient's wife asked if he was "better yet" and was told he was dying. She stated that she wants to continue ECMO and "continues to hope for a miracle."</p> |
| 2. Reliance on faith and spirituality | <p>2A A patient's wife stated, "This is a difficult and horrible situation." She stated she was coping the best she could. She was "praying" the patient would survive this infection.</p> <p>2B Another patient's wife (via Spanish translator) used faith to make sense of her husband's circumstance. She opened up more and stated, "yes very difficult." She was asked what gives her hope and strength each day. "God, God gives me strength. They told me he was improving . . . waiting to diminish the oxygen to see if he could breathe with his own lungs." "I understand he's still very sick. He's not doing well, he's really bad. It's difficult to receive bad news, but it's in God's hands. I pray that God guides the doctors with understanding and wisdom. If he goes, God needs him." She spoke of concern that "he's not going to live. It's bad. It hurts a lot."</p> <p>2C A patient's loved one stated: "We are doing fine, we just want to know how he is doing. We're trusting God. It's in God's hands and I am asking God for strength."</p> <p>2D When asked how she was doing, a patient's wife said tearfully: "It's hard, very, very hard. I'm trying to be strong. We do everything together. He is my best friend." When asked what gives her hope and strength to get through the day, she said: "God and my son." When this patient was finally off ECMO, she expressed: "Praise God, God is so good."</p> <p>2E A patient's family used faith to reason with their loved one's circumstances. This patient's mother in El Salvador is a Seventh Day Adventist and her son is nondenominational. She said of her son: "Hopefully this is a wake-up call."</p> <p>2F One patient's brother said: "If there is anything to do, do it. But if not, we understand." It was explained that the patient's prognosis was very poor and that he'll likely die. Emotional support and empathy were provided and the family understood. "If there is nothing else to do for him, we will pray for his soul."</p> <p>2G When discussing end-of-life care, one family member stated: "We are Christian and we cannot make a decision to end her life."</p> |
| 3. Multiple family members with COVID | <p>3A The brother of a patient whose entire household tested positive for SARS-CoV-2 said: "[Our family has] never been through something like this. We are getting better, but we are very worried about him."</p> <p>3B A patient's wife who recovered from COVID struggled to cope: "I'm trying to be strong. I keep crying and I can't sleep. I'm losing weight...very scared for [her husband]. I don't want to lose him. How am I fine and he is in the hospital..."</p> |
| 4. Families with young children coping with a new normal | <p>4A A patient's wife was asked what gives her strength through the day and said: "My children. I need to be strong for them."</p> <p>4B The wife of patient, discussing his 14-year-old daughter, said: "She knows her dad is in bad condition but she is trying to handle it okay. Can I ask you a favor? Can you tell him we [wife and daughters] love him?"</p> <p>4C A patient's wife with a 9-year-old daughter was asked what gives her strength: "My children even though my heart is suffering. [Her daughter] knows her father is a bit sick, but maybe he will be able to get better. [Their children] know he is grave and very sick."</p> <p>4D A patient's wife reported the youngest son had been crying and asked, "Is my dad dead?" She stated she was trying to remain strong but sometimes she is not. She was "praying."</p> |
| 5. Visitation restrictions | <p>5A In this situation, failure to have closure by being at her husband's side at his time of death was an obstacle for the patient's wife in accepting a palliative approach for the patient. Family meeting note documented: Medical team ultimately does not have control to heal him, she does not have control of visiting and being at his bedside. I gently discussed what we do have control over at this time is alleviating suffering, focus on comfort and the control of how he dies and "goes home to God." She spoke how she is opting for a "natural death" on machines "not be disconnected." She became tearful, saying how she can't even be with him as he is dying. She specifically mentioned how she can be with him [in] his "final minutes."</p> <p>5B Zoom calls were available to family members. One patient's wife said: "I see how her face lights up when she sees me [on Zoom]."</p> |

Continued

Table 2
Continued

| Theme | Sample quotes |
|---|---|
| 6. Gratitude for clinicians and care | |
| 6A | One family member expressed appreciation for the care the staff was providing: "I know we are in good hands." |
| 6B | The wife of a patient spoke of her appreciation for all of the medical teams caring for her husband: "I could never repay." When asked how they were doing, a family member said: "Good and bad days; it's tough, really heartbreaking . . . but we're comforted that he is being cared for. We are grateful." |
| 6C | |
| 7. End-of-life discussions | |
| 7A | After a patient's code status was changed to do not resuscitate/do not intubate, his daughter had ongoing concerns. "I love him, I'm praying he gets better. He will come home." She began to cry and stated, "Don't disconnect him." I informed her that we were not discontinuing life support. I did reiterate outcomes of no attempt of resuscitation and no escalation of care as discussed per family meeting. "Why will you not try?" |
| 7B | In a meeting with a patient's wife to discuss ECMO withdrawal, she asked: "For any of those here who are married, what would you say?" The doctor gently reframed her concern that ultimately we were not asking her or the 3 daughters to make a decision, that this was about patient's decision. The wife spoke afterwards and shared how her faith has helped her to cope with all that has happened but how it is also so hard to see her husband getting so much worse. She said she will be praying for a miracle until the end but said she understands that a miracle may be an end to his suffering. This ultimately allowed her to cope with this decision. The same patient's daughter expressed concerns: "Is he suffering? I feel like he's suffering and has a long road ahead of him." |
| 7C | A patient's Spanish-speaking wife expressed concern: She noted she was not happy because the team said "he is going to die" and she "does not want him medically neglected." The team had the patient's wife summarize in her own words her understanding of what was discussed. At first she struggled to summarize and said, "I understand, it's very bad." She then finally asked, "Is he going to live or die?" The doctor answered he would likely die. She said: "He would want to be with his family, his grandchildren, his children and myself. He's fighting for his life. He's fighting because he wants to be with us." |

Abbreviation: ECMO, extracorporeal membrane oxygenation.

and families acknowledge and understand the complexity, benefits, and limitations of ECMO in patients with COVID-19. This study also highlights the range of experiences that patients and their families go through during critical COVID-19 illness, which is also the case with other clinical scenarios similar to COVID-19. The sentiments expressed by these patients' family members are universal to situations in which families are faced with the uncertainty of a loved one's critical illness and are forced to understand and accept its implications.

Our study has significant public health implications. The importance of family engagement and support in improving outcomes of care for hospitalized patients with serious and advanced illness is highly underestimated.²⁶⁻²⁹ Improving clinical outcomes requires partnership between physicians, patients, and families to promote family members' active participation in decision-making, honor patient preferences, and provide patient-centered care.³⁰⁻³³ Unfortunately, family engagement has been significantly hindered by the COVID-19 pandemic, leading to terribly isolating experiences as patients and families handle individual suffering alone.³⁴

In a position paper, an international group of physicians, ECMO specialists, and allied health care workers spanning 6 continents suggested that

preemptive palliative care consultation before ECMO initiation may be appropriate for patients in whom outcomes are especially uncertain, such as when ECMO is used as a bridge to healing or decision-making about transplant or hospice.³⁵

The rapid deterioration in condition of patients with COVID-19 during the initial phase of the pandemic often necessitated urgent actions in the face of uncertainty and made it challenging to conduct such meetings before ECMO initiation.

This study provides evidence for practical recommendations to support families of patients with COVID-19 who are receiving ECMO. In our experience, implementing a unified interdisciplinary process has helped streamline communication among all stakeholders through early and regularly scheduled meetings between the clinical team and family. This process includes additional pre-ECMO meetings between the primary and palliative care teams to ensure that there is agreement regarding the plan of care when a potential conflict or

Analysis of clinicians' notes uncovered the following themes in family members' comments: hope, reliance on faith and spirituality, and gratitude for clinicians and care.

Implementing a unified interdisciplinary process has helped streamline communication among all stakeholders.

communication breakdown is detected. We observed that consistent messaging between team members, patients, and family members decreased confusion about the planned course of care both for the families and for those directly involved in the patients' care.

In an intensive care study that used a combination of quantitative and qualitative methods to explore the determinants of family satisfaction, the themes that were most associated with higher satisfaction included increased consistency, clarity, and completeness of information; emotional support; and respect and compassion shown toward the family.³⁶ In our population, family members experienced a myriad of emotions, described by one as "stuck in a nightmare and waiting to wake up." The initial family meetings involved the panic and despair of relatives recognizing the seriousness of the disease and learning of increasing death tolls reported daily in the news.³⁷ Family members felt devastated upon learning

of the need for ECMO support, signaling severely critical illness and a high risk of death for their loved one. After an initial period of confusion, family members primarily experienced an ongoing fear of the unknown. Most individuals interviewed felt

overwhelmed and were worried about their hospitalized loved one as well as other vulnerable family members isolating at home to avoid infection. A relative with multiple family members with COVID-19 described it as a situation they had "never been through" before (Table 2, quote 3A).

Young children of hospitalized patients also struggled to cope and process the situation (Table 2, quote 4D). The emotional stress these children endured caused additional stress for adult family members, although it simultaneously created motivation to "be strong" (Table 2, quote 4A). The palliative care team would often request the assistance of child support specialists in these situations.

Hope was prominent, and it came from increased disease-related knowledge, adequate medical resources and social support, and encouragement among family members. "Two days after cannulation for ECMO, a patient's father shared that he and patient's mother are 'pretty much okay.' They are waiting eagerly for 'good news'" (Table 2, quote 1A). Another clinician documented that "a patient's wife asked if he was 'better yet' and was told he is dying. She . . . continues to

hope for a miracle" (Table 2, quote 1B). As family members' knowledge of COVID-19 gradually increased, they came to better understand potential outcomes for their loved ones: "I understand he's still very sick. He's not doing well, he's really bad. It's difficult to receive bad news, but it's in God's hands" (Table 2, quote 2B).

Feelings of gratitude for the medical care and updates being provided were also abundant. Despite their heartbreak, family members found comfort in knowing their loved ones were attentively cared for. "Good and bad days; it's tough, really heartbreaking . . . but we're comforted that he is being cared for. We are grateful" (Table 2, quote 6C). They described feeling indebted ("I could never repay") (Table 2, quote 6B) and reliant on this care ("I know we are in good hands"; Table 2, quote 6A).

Faith was also an important aspect of coping. Those who already had religious or spiritual belief found a deepening of their existing belief: "We're trusting God. It's in God's hands and I am asking God for strength" (Table 2, quote 2C). Having spiritual faith helped grieving family members reduce the pain of negative emotions and feel more content in the face of mortality. Faith was a driver of hope ("Praise God, God is so good" [Table 2, quote 2D]) as well as a driver of acceptance ("If there is anything to do, do it. But if not, we understand" [Table 2, quote 2F]). Some family members used faith to reason with their loved one's circumstance: "Hopefully this is a wake-up call" (Table 2, quote 2E). For others, faith was an obstacle to accepting the end of life: "We are Christian and we cannot make a decision to end her life" (Table 2, quote 2G). Several families asked for chaplains to pray with them over video calls and in subsequent separate meetings with the chaplain. Our findings are in line with an important body of research underscoring the role of spirituality in health care.³⁸⁻⁴⁰

Family members expressed grief related to being unable to physically be with their loved ones due to visitation restrictions. One patient's wife cried because she couldn't be with him in his final minutes as he "goes home to God" (Table 2, quote 5A). Sometimes this sorrow could be reduced through the use of telehealth video calls: "I see how her face lights up when she sees me [on Zoom]" (Table 2, quote 5B).

Caring for a dying patient receiving ECMO was particularly challenging not only for families but also for health care professionals.⁴¹ Having open and honest conversations with families during ECMO acknowledgment meetings helped manage expectations, alleviate uncertainty, and provide extra support for

family members needing time to make difficult decisions when treatment could prevent neither the deterioration of health nor the impending death of an individual.

Our study's limitations include its limited generalizability given that patients were from a small sample at a single institution. Also, data did not include feedback from clinicians or families on the effectiveness of this performance improvement strategy. As the COVID-19 pandemic continues to evolve, it is beneficial to establish guidelines for managing communication in an ECMO setting to improve the experience for patients, families, and the clinical teams.

Future directions for this research will include a study design incorporating a qualitative method. Focus group discussions will help determine whether the primary medical team benefits from the involvement of the palliative care team, specifically whether involvement of the palliative care team mitigates the primary care team's experience of moral distress in cases of complex ECMO (eg, in patients who receive ECMO for prolonged durations).

Conclusion

The COVID-19 pandemic presents a unique challenge for patients, their families, and health care clinicians of all backgrounds. Our study shows that early and ongoing palliative care is useful in highlighting a range of experiences that are specifically related to COVID-19 and in achieving patient and family acknowledgment of the complexity, benefits, and limitations of ECMO support.

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Safanah Siddiqui and Gabriel Lutz served as co-first authors and contributed equally to the work.

FINANCIAL DISCLOSURES

None reported.

SEE ALSO

For more about ECMO and COVID, visit the AACN *Advanced Critical Care* website, www.aacnconline.org, and read the article by Sheasby et al, "An Interprofessional Approach to Mobilizing Patients With COVID-19 Receiving Extracorporeal Membrane Oxygenation" (Fall 2022).

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CE 1.0 Hour Category B

Notice to CE enrollees:

This article has been designated for CE contact hour(s). The evaluation demonstrates your knowledge of the following objectives:

1. Highlight a range of experiences related to COVID-19.
2. Identify palliative care as a tool to educate families on the benefits and limitations of extracorporeal membrane oxygenation (ECMO).
3. Describe the benefits of open and honest communication with patients' families.

To complete the evaluation for CE contact hour(s) for activity A233232, visit <https://aacnjournals.org/ajconline/ce-articles>. No CE fee for AACN members. See CE activity page for expiration date.

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Supplemental Table

Script to explain extracorporeal membrane oxygenation (ECMO) to patients and their families

| Who | ECMO script for patient and family | Purpose/acknowledgment information |
|----------------------|---|--|
| Intensivist | <p>"Thank you all for being here to support (<i>patient name</i>)."</p> <p>"Let's explain how this ICU [intensive care unit] works: the 'ICU' doctor or intensivist is a specialist who organizes and coordinates all aspects of ICU care; they work hand in hand with the surgeons and others."</p> <p>"Let's go around the room to introduce ourselves."</p> <p>"I want to explain about (his/her) ICU care so far, but before I do..."</p> <p>"What is your understanding now of where you are [he/she is] with your/their illness?"</p> <p>"How much information about what is likely to be ahead with your/their illness would you like from us?"</p> <p>"Do you want lots details or more general 'big picture' information?"</p> | <p>Start with privacy and comfort, with all seated in room and tissues available. If patient is not able to participate have meeting outside patient's room. Ask patient/family about their understanding and information preferences. Avoid jargon; tailor message to THEIR stated preferences.</p> |
| Intensivist | <p>(<i>Fill in gaps of patient/family understanding of serious illness with brief problem list, stop at ECMO to check for questions...</i>) "Unfortunately these problems all complicate each other. Before we continue, are there any questions so far?"</p> | <p>List medical problems. Give information clearly and to the point with 1 sentence; use headline you want them to take away. Introduce complexity of multimorbid illness and multi-system dysfunction.</p> |
| Intensivist | <p>"This ECMO machine does not treat disease, it provides support so we can treat the diseases or injuries. It supports the body when the lungs cannot exchange enough oxygen and carbon dioxide, or the heart cannot pump enough blood to the body.</p> <p>In this case, the ECMO addresses the medical problems of ..."</p> | <p>Patients with severe and potentially reversible, acute respiratory or cardiac failure that is unresponsive to conventional management may be evaluated for ECMO.</p> |
| Intensivist and team | <p>(PAUSE-use silence. Offer tissues if needed.)</p> | <p>Observe nonverbal communication, maintain eye contact, and acknowledge emotion.</p> |
| Intensivist | <p>"People who need support from an ECMO machine are cared for in a hospital intensive care unit (ICU). Usually people are supported by an ECMO machine for only a few hours to days, but may require it for a few weeks, depending on how their condition progresses.</p> <p>At this time, for (<i>patient name</i>) we are relying on the ECMO machine to (<i>explain treatment targets</i>)."</p> | <p>Patient or family acknowledges medical team's explanation of ECMO. ECMO is a type of mechanical cardiopulmonary support that is usually delivered in the ICU. It is not meant to be used as a long-term treatment to extend life absent transplant or in conditions that may be found to be irreversible once medical evaluation and diagnosis are completed.</p> |
| Intensivist and team | <p>"It's hard to deal with all this, what worries you the most?"</p> | <p>Acknowledge emotion, offer empathy.</p> |
| Intensivist/ surgeon | <p>"ECMO is only a 'life-sustaining treatment.' It does not cure or treat the disease or injury that led to heart and/or lung failure. This means ECMO can prolong life to allow for more time to try to fix the problem. ECMO may also support people with incurable heart or lung disease while they wait for an organ transplant (<i>eg, new heart and/or lungs</i>). ECMO does not save everyone but it has improved survival for many critically ill people who are not responding to usual life support options. In this case, the ECMO is used to... (<i>explain treatment targets and or clinical end points/ outcomes</i>)."</p> | <p>ECMO is most often used in patients as a</p> <ol style="list-style-type: none"> (1) bridge to transplant OR (2) bridge to recovery following acute but reversible cardiac/lung injury OR (3) in patients who have sustained acute cardiac/lung injury the extent of which or chance for recovery is not immediately known. <p>Explain why this patient is on ECMO.</p> |
| Intensivist/ surgeon | <p>"Sometimes patients do not get better on ECMO because their disease or injury cannot be fixed; patients can die while connected to ECMO" (<i>pause after introducing "die"</i>).</p> | <p>Foreshadow possible clinical end point IF ECMO does not offer benefit or is ineffective; important to say "die."</p> |
| Intensivist/ surgeon | <p>"This is a lot of information; tell me your understanding so far."</p> | <p>Clarify accurate receipt of information. Observe for emotion; acknowledge emotion.</p> |
| Intensivist/ surgeon | <p>"We always try to help people get off the ECMO machine as soon as possible. Sometimes patients do not get better while they are on ECMO because their disease or injury cannot be fixed. A decision about whether there is benefit to continuing ECMO can be hard, and some patients will not want to stay on ECMO if they are not improving."</p> | <p>ECMO is not meant to be used as a long-term treatment to extend life absent transplant or in conditions that may be found to be irreversible once medical evaluation and diagnosis are completed.</p> <p>I understand that ECMO is not meant to be used as a long-term treatment to extend my life (or my loved one's life) absent transplant or improvement of my condition.</p> |

Continued

Supplemental Table
Continued

| Who | ECMO script for patient and family | Purpose/acknowledgment information |
|--|---|---|
| Intensivist/ surgeon | <p>“If we find that the patient’s disease or illness is very severe and will not get better, we will discuss this carefully with you all to make decisions about the end of life and removing the patient from ECMO support. Removing ECMO is called ‘decannulate.’”</p> <p>If next of kin/proxy decision maker involved:</p> <p>“When (<i>patient name</i>) cannot talk or communicate their decision, we talk with (<i>his/her</i>) legally authorized representative according to the law in Maryland. While patients can die even though they are connected to ECMO, sometimes ECMO may seem to prolong the dying process. We will let you know if and when the ECMO needs to be discontinued, but we will continue our intensive care, to provide care and comfort no matter what the outcome.”</p> | <p>I understand that should I (or my loved one) no longer qualify as a transplant candidate, or should my (or my loved one’s health care providers) conclude that I (or my loved one) do not have a substantial chance of recovery from my (or my loved one’s) injuries absent ECMO, my (or my loved one’s) health care providers may discontinue ECMO (decannulate). I understand that taking me (or my loved one) off ECMO in this circumstance will result in a deterioration of my (or my loved one’s) condition and most likely death.</p> <p>Provide affirmation of caring despite ECMO trials and outcomes.</p> |
| Intensivist/ team | <p>“We are also here for you all—sometimes that might mean answering questions—this is not something people go through every day—we understand if you don’t know what to expect. But, we are here to try and help out. What questions do you have now? Any time you have a question, we want you to ask us. The best way to reach the team is (<i>who, when to call, and phone numbers</i>)”</p> | <p>Important to extend care to family. Inform and assure family of how to reach team.</p> |
| Intensivist/ team | <p>“Today we talked about the purpose of the temporary ECMO treatment related to disease and injury. (<i>elaborate as needed</i>) We will review how the treatment is working in (<i>a few days, one week, or two weeks</i>) with you... How does that sound? We will meet again on (<i>future date and time</i>).”</p> | <p>Summarize overview and set stage for ongoing review of clinical outcomes of ECMO treatment trial.</p> |
| Additional content to discuss initially or as needed | | |
| Teams | <p>“The health care team looking after patients on ECMO aims to avoid any complications that may occur from being on the machine. Some of the more serious problems that may occur when a patient is on ECMO include: (<i>see teaching sheet</i>)</p> <p>Bleeding Kidney failure Leg damage Stroke</p> <p>What questions can we answer about the risks of ECMO?”</p> | <p>Risks: (<i>see teaching sheet</i>) I have been informed of the following risks of ECMO: Bleeding (<i>see teaching sheet</i>) Kidney failure (<i>see teaching sheet</i>) Leg damage (<i>see teaching sheet</i>) Stroke</p> |
| Teams | <p>“If the situations worsens, what are the most important goals?” “What are the biggest fears and worries about the future and health?” “What matters most at this time?” “What abilities are so critical to your life that you can’t imagine living without?” “If you become sicker, how much are you willing to go through for the possibility of gaining more time?” “What gives you strength as you think about the future?”</p> | <p>Exploring patient values/beliefs: Exploring values assesses psychosocial needs, problems, and distress that can be addressed by interdisciplinary care. Consult social worker. Consult chaplain. Consult Integrative Medicine department.</p> |
| <p>Resources What is ECMO? https://www.thoracic.org/patients/patient-resources/resources/what-is-ecmo.pdf Vital Talk https://www.vitaltalk.org/resources/ Fast Facts #224 https://www.mypcnow.org/wp-content/uploads/2019/03/FF-224-fam-mtg-Respond-to-emotion.-3rd-Ed-1.pdf Fast Facts #339 https://www.mypcnow.org/fast-fact/extracorporeal-membrane-oxygenation-in-adults/</p> | | |