Transplant & Mechanical Support: Short Report

Surviving Extracorporeal Membrane Oxygenation Is a Longitudinal Process: Exploring a Survivorship Model to Improve Quality of Life

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ABSTRACT

BACKGROUND Venovenous extracorporeal membrane oxygenation is a salvage therapy for patients with acute respiratory distress syndrome. Survivors struggle with daily activities after decannulation and discharge. We evaluated outcomes after implementing a survivorship approach based on a cancer survivorship clinic model to improve quality of life (QoL) and optimize resource consumption.

METHODS We established a multidisciplinary survivorship clinic using telehealth and in-person physical and occupational therapy teams. Data from the 12-item Short Form Health Survey (SF-12) were collected between 2020 and 2023. Interviews were conducted at 6 months, 1 year, and 2 years after decannulation. The patients were offered in-person and telephone-based counseling with scheduled inpatient and outpatient rehabilitation visits. SF-12 mental component summary (MCS-12) and physical component summary (PCS-12) scores were used to calculate quality-adjusted life years (QALYs). The relationship between QoL, costs, and length of stay outcomes was assessed using generalized linear and mixed models.

RESULTS Fifty-three patients were monitored for 3 years. Mean age was 41.7 years, 98.1% were White, and 50.9% were men. At 6 months, 1 year, and 2 years, mean MSC-12 scores were 52.9, 50, and 49.7, PCS-12 scores were 43.7, 41.8, and 47.3, and QALYs were 0.837, 0.829, and 0.826, respectively. MCS-12 showed no significant difference from the United States population. PCS-12 was significantly lower than the United States population during the first and second evaluations ($P < .001$) but showed no difference at 36 months. QALYs were significantly higher ($P < .001$). Higher resource consumption was associated with lower PCS-12 scores and QALYs.

CONCLUSIONS The survivorship approach with counseling and rehabilitation yields acceptable QoL, which may inform strategies to improve the cost-effectiveness of venovenous extracorporeal membrane oxygenation.

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The severe acute respiratory syndrome coronavirus 2 (coronavirus disease 2019 [COVID-19]) reshaped medicine and influenced the approach to venovenous extracorporeal membrane oxygenation (VV-ECMO). VV-ECMO was used as a last resort, with mortality

Abbreviations and Acronyms

COVID-19 = coronavirus disease 2019
ECMO = extracorporeal membrane oxygenation
ICU = intensive care unit
LOS = length of stay
MCS-12 = 12-item Short Form Health Survey mental component summary
PCS-12 = 12-item Short Form Health Survey physical component summary
QALYs = quality-adjusted life years
QoL = quality of life
SF-12 = 12-item Short Form Health Survey
VV-ECMO = venovenous extracorporeal membrane oxygenation

IN SHORT

- Surviving extracorporeal membrane oxygenation (ECMO) is a longitudinal process, not a binary event.
- An ECMO survivorship program, similar to existing cancer survivorship programs, should be implemented to adjust to life after ECMO.
- A survivorship program can increase the quality of life for survivors and improve return to normalcy.

approaching 50%.[1] The recovery process to return to normal life after ECMO brought entirely new challenges.

Rehabilitation is often overlooked for critically ill patients.[2] Nearly 80% of patients who required mechanical ventilation for COVID-19 report long-lasting effects, including fatigue, psychosocial disturbance, mental disturbances, and guilt.[3] Long-term care for survivors is thus crucial.

No survivorship program currently exists for ECMO survivors. Instead, survival is often addressed as a binary event rather than a longitudinal process. Our objective was to establish an ECMO survivorship program to improve long-term care. We hypothesized that a survivorship approach offering counseling and dedicated rehabilitation to ECMO survivors would improve quality of life (QoL) and provide a valuable and cost-effective approach to long-term care.

MATERIAL AND METHODS

STUDY DESIGN. This single-center report analyzed the QoL after VV-ECMO at a tertiary center. We performed a retrospective analysis of our VV-ECMO registry. We assessed 53 patients with severe acute respiratory syndrome coronavirus 2 between 2020 and 2023. Assessments were at 6 months, 1 year, and 2 years from decannulation. This study followed the guidelines for reporting uncontrolled case series data and was approved by the West Virginia University Institutional Review Board (IRB #2003938395).

DEVELOPMENT OF AN ECMO SURVIVORSHIP PROGRAM. We collaborated with our Cancer Center to develop a VV-ECMO survival registry, guiding follow-up calls and administering distress tools. The National Comprehensive Cancer Network Distress Thermometer allowed patients to self-report distress, using a rating scale from 0 (no distress) to 10 (extreme distress).[4] A graduate

student served as a clinical navigator, conducting calls, and collaborating with physical and occupational therapy departments to create a patient resource guide. This guide serves as an empowering educational tool to educate and support ECMO survivors and their families. This comprehensive guide provides essential information about patient appointments, resources, and crucial services such as meals, transportation, and physical, occupational, and behavioral therapy. Patients can identify the source of their distress through a comprehensive problem list covering physical, emotional, social, practical, spiritual, and other concerns.

All 53 patients attended the survivorship clinic, with flexible in-person or virtual appointments. This was implemented to facilitate ease of participation for all patients. We hosted monthly extracorporeal life support online support group meetings and in-person therapy sessions with licensed therapists. Informed consent was obtained before survey administration. Patients were contacted by phone or evaluated in the clinic 3 times after discharge to collect daily living activity information using the 12-item Short Form Health Survey (SF-12) model.[5]

OUTCOME VARIABLES. Primary outcomes were QoL scores: mental component summary (MCS-12), physical component summary (PCS-12), and quality-adjusted life years (QALYs) scores. The SF-12 is a subset of the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) assessing functional health and well-being from the patient's viewpoint.[5] The SF-12 consists of 12 items providing 2 summary scores: MCS-12 and PCS-12 scores. Higher scores reflect better QoL. To determine QALYs, we used the SF-12 scores and assigned weights to each participant's responses, calculated from established models.[6] The SF-12 assesses 6 health states: physical functioning, pain, role limitations, mental health, social functioning, and vitality.

STATISTICAL METHODS. We used generalized linear regression models to evaluate differences in QoL

scores between 3 SF-12 assessments. Using mixed models with a Gaussian distribution family, we evaluated the association between QoL, hospital and intensive care unit (ICU) length of stay (LOS), and costs (total and ECMO costs). Models included QoL scores as dependent variables and accounted for the patient as a layer (grouping or random effects). We also adjusted for age, sex, and body mass index. We reported results as predicted means with 95% CIs and interpreted as significant when any 2 predicted means did not overlap between different estimates, along with P for trend $<.05$.[7] Analyses were performed using R statistical software (R Project for Statistical Computing, Vienna, Austria).[8]

RESULTS

The study included 272 ECMO patients (31.25% survival rate); of these 106 were positive for COVID-19 (30.19% survival rate). The survivorship clinic monitored 53 patients. Table 1 presents the demographics of the study population. The mean age was 41.7 years, 98.1% of patients were White (98.1%), and 50.9% were men, with a body mass index of 38 kg/m². The mean hospital LOS was 28.9 days, and the mean ICU LOS was 22.6 days. The average time between the first and second SF-12 assessments was 218 days, between the second and third was 229 days, and between the first and third was 428 days.

LONGITUDINAL ESTIMATES OF QOL. Table 2 compares QoL metrics between VV-ECMO survivors and the United States population (reference mean: 50 for MCS-12 and PCS-12 and 0.7 for QALYs). Mean MCS-12 scores for the 3 assessments were 52.9, 50, and 49.7, mean PCS-12 scores were 43.7, 41.8, and 47.3, and mean QALYs were 0.837, 0.829, and 0.826, respectively. In all 3 assessments, the difference in MCS-12 scores was not significant. However, during the first and second assessments, VV-ECMO survivors had significantly lower PCS-12 scores (43.71 [95% CI, 41.05-46.37] vs 41.75 [95% CI, 38.11-45.4], $P < .001$). Nonetheless, the 36-month PCS-12 evaluation showed no significant difference. Conversely, patients had significantly higher QALY scores during the 3 assessments (0.84 [95% CI, 0.81-0.86], 0.83 [95% CI, 0.79-0.87], and 0.83 [95% CI, 0.78-0.87], respectively, $P < .001$).

COMPARISON BETWEEN FIRST, SECOND, AND THIRD ASSESSMENTS. Table 3 presents a comparison of results between the first, second, and third assessments. There were no significant differences in the MCS-12, PCS-12, and QALY

TABLE 1 Study Sample Characteristics	
Variable	**Data Values (N = 53)**
Age, mean, y	41.7
Sex, %	
Male	50.90
Female	49.10
Race, n (%)	
Black	1 (1.89)
White	52 (98.1)
Body mass index, mean, kg/m²	38
Body surface area, mean, m²	2.26
Medicaid, n (%)	10 (18.9)
Alive at discharge, n (%)	53 (100)
Length of stay	
Hospital, mean, d	28.9
Intensive care unit, mean, d	22.6
Costs	
EMCO, mean, $	40,164
Total, mean, $	303,321
Time in days between decannulation and	
First SF–12, mean, d	151
Second SF–12, mean, d	391
Third SF–12, mean, d	605
Times in days between	
First and second SF–12, mean, d	218
Second and third, mean, d	229
First and third, mean, d	428

ECMO, extracorporeal membrane oxygenation; SF–12, 12–item Short Form Health Survey.

scores between the 3 assessments. The resource consumption, including hospital and ICU LOS, ECMO costs, and total hospitalization costs, showed no significant differences.

ASSOCIATION AMONG SF–12 SCORES, COSTS, AND LOS. The scatter plots in Figure compare SF-12 scores (MCS-12, PCS-12, and QALYs), LOS, and costs for ECMO patients. The data indicate that the initial significant decrease in PCS-12 is associated with hospital and ICU LOS ($R = -0.37$, $P = .007$). The significant decrease in PCS-12 (first: $R = -0.38$, $P = .012$; second: $R = -0.41$, $P = .018$) and QALYs (first: $R = -0.40$, $P = .009$; second: $R = -0.37$, $P = .036$) is correlated with increasing ECMO costs. Higher total costs are linked to a significant decline in PCS-12 (first: $R = -0.43$, $P = .004$; second: $R = -0.43$, $P = .007$; third: $R = -0.46$, $P = .023$) and a decrease in QALYs (first: $R = -0.37$, $P = .015$; second: $R = -0.39$, $P = .029$).

COMMENT

Our ECMO survivorship model shows MCS-12 scores were not statistically different from those

TABLE 2 Quality of Life Scores During First, Second, and Third 12-Item Short Form Health Survey Assessments After Decannulation Compared With the Mean for the United States Population

Variable	Mean (95% CI)	P Value
First assessment		
MCS–12	52.93 (49.94–55.93)	.055
PCS–12	43.8 (41.2–46.4)	<.001
Quality–adjusted life years	0.837 (0.811–0.863)	<.001
Second assessment		
MCS–12	50.1 (47–53.3)	.999
PCS–12	42.1 (39.1–45.1)	<.001
Quality–adjusted life years	0.832 (0.802–0.862)	<.001
Third assessment		
MCS–12	50.3 (46.7–53.9)	.898
PCS–12	46.9 (43.4–50.4)	.203
Quality–adjusted life years	0.829 (0.795–0.864)	<.001

All values compared with the United States population (referent mean: 50 for MCS–12 and PCS–12 and 0.7 for quality–adjusted life years). MCS–12, 12-item Short Form Health Survey metal component summary; PCS–12, 12-item Short Form Health Survey physical component summary.

of the general population. PCS-12 scores became comparable by the third assessment. QALYs were consistently higher in all assessments, suggesting that the survivorship program interventions improved the patient's QoL. This approach to recovery after ECMO hospitalization suggests a plausible return to premorbid functioning. These data fill a gap in ECMO survivorship and QoL metrics, providing metrics to establish survivorship programs.

ECMO survivors experience high levels of psychological distress, memory problems, and difficulty with daily activities.[9] Nearly 52% of ECMO survivors reportedly had a functional impairment, a percentage higher than reported for ICU survivors in general.[10] Early rehabilitation and

forward-thinking ethos are needed. Rehabilitation efforts, including counseling and exercise programs, have positive effects on QoL. Commitment to the longitudinal process of recovery means a departure from approaching survival as a binary event, which historically disregards whether or not survivors returned to premorbid functional status. Our program provided survivors with this critical function to ameliorate feelings of guilt and depression with favorable results, providing clinically meaningful improvements in the functional status, QoL, and mental health in this population.

Certain limitations should be noted, including a restricted sample size drawn from a single center, because participation was not universal among survivors, consequently impeding generalization. Some common concerns among nonparticipants were their preference to seek medical follow-up only after discharge from the hospital, with a reluctance to relive the trauma they had endured, and the dearth of information regarding the availability of similar clinics at other hospitals. Although open to the idea, they wanted to hear about other patients' experiences first. They showed potential interest in participating in the future if they faced challenges reintegrating into normal life. We provided reassurance that the clinic would remain accessible to meet their needs and inquiries.

Our patient cohort exhibits limited ethnic and geographic diversity, thus restricting the extrapolation of findings to the broader United States population. The presence of researchers during data collection introduces a potential for bias. Moreover, the unique circumstances surrounding health care delivery during a once-in-a-lifetime pandemic may further limit the generalizability of the study's findings. These limitations are each

TABLE 3 Model Results for Coronavirus Disease Patients With Extracorporal Membrane Oxygenation During Their First, Second, and Third 12-Item Short Form Health Survey Assessments After Decannulation

Variable	First Assessment	Second Assessment Mean (95% CI)	P	Third Assessment Mean (95% CI)	P
MCS–12	52.9 (50.2–55.6)	50.1 (47–53.3)	.387	50.3 (46.7–53.9)	.492
PCS–12	43.8 (41.2–46.4)	42.1 (39.1–45.1)	.685	46.9 (43.4–50.4)	.328
QALYs	0.837 (0.811–0.863)	0.832 (0.802–0.862)	.969	0.829 (0.795–0.864)	.94
Length of stay					
Hospital	28.7 (25.6–31.8)	28.6 (25–32.1)	.998	28.6 (24.4–32.7)	.998
Intensive care unit	22.4 (19.6–25.2)	22.7 (19.4–25.9)	.99	22.9 (19.2–26.7)	.971
Costs					
ECMO, $	40,728 (35,106–46,350)	41,827 (35,329–48,325)	.966	36,761 (29,251–44,270)	.684
Total, $	304,121 (263,308–344,934)	305,357 (258,185–352,528)	.999	276,847 (222,331–331,362)	.711

ECMO, extracorporeal membrane oxygenation; MCS–12, mental component summary of the 12-item Short Form Health Survey; PCS–12, physical component summary of the 12-item Short Form Health survey; QALYs, quality–adjusted life years.
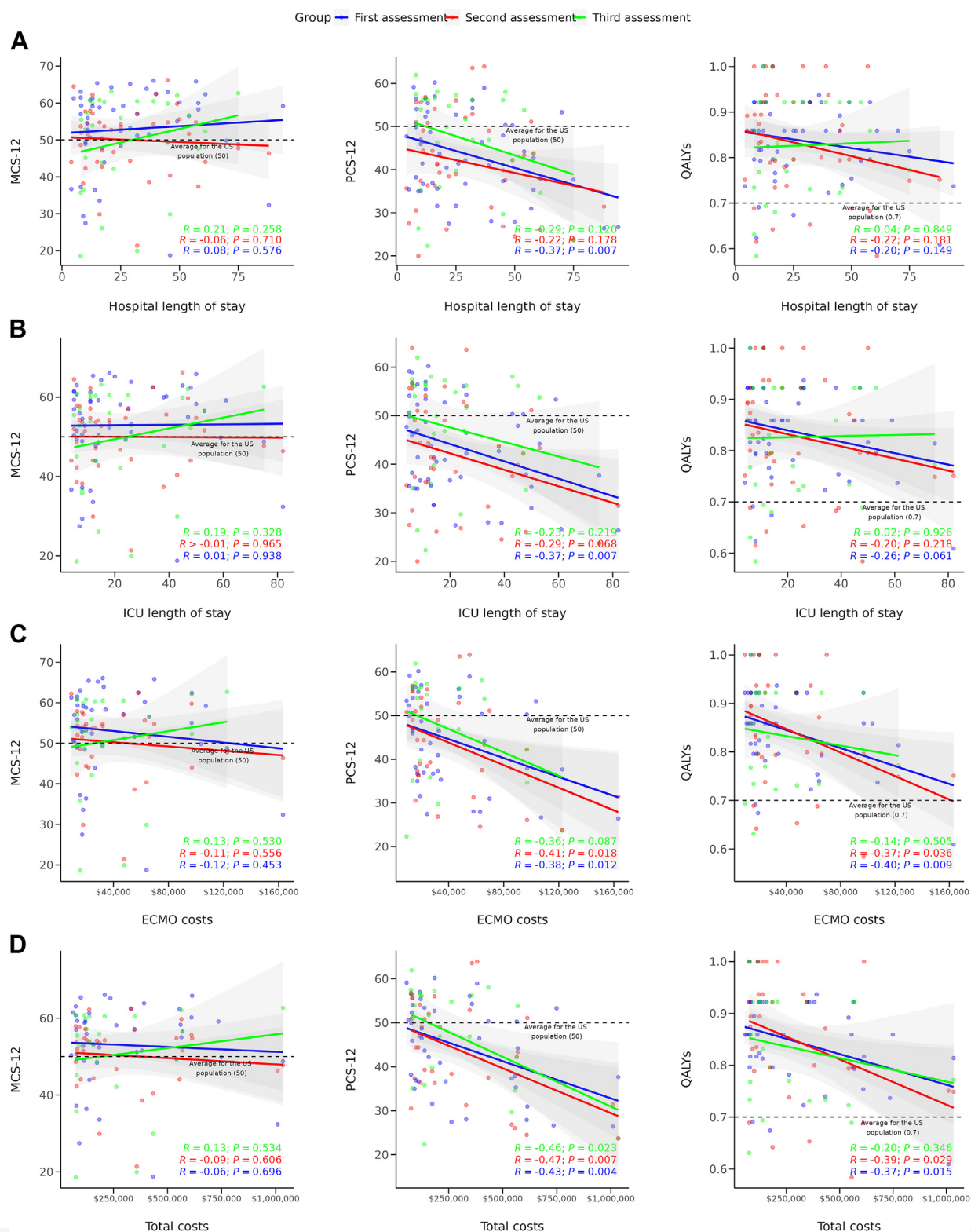
FIGURE Scatter plots of 12–item Short Form mental component summary (MCS–12) scores (left), physical component summary (PCS–12) scores (center), and quality–adjusted life years (QALYs) (right) compared with the (A) hospital length of stay, (B) intensive care unit (ICU) length of stay, (C) extracorporeal membrane oxygenation (ECMO) costs, and (D) total costs for patients with coronavirus disease 2019 who required ECMO, during their first, second, and third assessments after decannulation. (US, United States.)

potential sources of confounding and bias. The magnitude of unmitigated confounding is likely the reason driving the disparate observation in the QALY results within the ECMO population. There is also the potential of bias from a Hawthorne effect that may also be the culprit. Needless to say, these each suggest the need for further studies

In conclusion, a longitudinal process supports VV-ECMO survivors in returning to premorbid function, mitigating social and functional limitations. The survivorship model can improve care and produce QoL metrics equivalent to those of the public. This model represents an opportunity to improve the long-term QoL and cost-effectiveness of ECMO.

DISCLOSURES
The authors have no conflicts of interest to disclose.

PATIENT CONSENT
Obtained.

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