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Health-Related Quality of Life and PTSD-Symptoms in Survivors of Extracorporeal Membrane Oxygenation (ECMO) Support

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Health-Related Quality of Life and PTSD-Symptoms in Survivors of Extracorporeal Membrane Oxygenation (ECMO) Support

Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Nursing Practice at the University of Kentucky

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Lexington, KY

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Abstract

Background: Extracorporeal membrane oxygenation (ECMO) survivors have shown to have poor physical and mental health outcomes post decannulation and hospitalization; thus leading to an overall decreased quality of life. Identifying and managing the psychological components of care in this patient population can improve their physical, emotional, and mental well-being.

Purpose: To assess the incidence of impaired health related quality of life (HRQOL) and posttraumatic stress disorder (PTSD) like symptoms in survivors of ECMO; identify which constellation of patients (respiratory vs. cardiac) have poorer HRQOL outcomes post ECMO; and compare the tools used to measure post procedural outcomes in this patient population.

Methods: This is a prospective cohort study. 21 patients were invited to participate in this study. Surveys were administered and data collected at discharge, first follow-up appointment (2-4 weeks), and second follow-up appointment (12-16 weeks) post discharge. Demographics were gathered through the patient's chart and data from the SF12v2 health survey and ICU memory tool (ICUMT). The surveys addressed the incidence of poor HRQOL in relation to PTSD-like symptoms in patients.

Results: A total of 8 participants agreed to participate in the surveys, with only 3 participants completing the surveys at all 3 data collection points. At each data collection timepoint, the PCS and MCS scores were not significantly different for the 3 participants, however the MCS scores from the SF12v2 and the ICUMT at data collection points two and three appear to align with similar results.

Conclusion: Despite low scores overall, study results did not show any statistical significance in PCS and MCS scores from the SF12v2 survey. The ICUMT and MCS data report similar results and those patients admitted with a cardiac diagnosis had poorer HRQOL outcomes compared to those admitted with a respiratory diagnosis. Further research is recommended.

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Dedication

I would like to dedicate this project to my husband, family, and colleagues. First, to my husband, thank you so much for putting in more time on the home front so I could work hard toward achieving my goals. Without your love and support, I wouldn't have been able to do this. To my three children, Miles, Isabella, and Abigail; you are what motivates and inspires me to push forward and do better. Thank you for your patience and understanding. Second, to my mother, I would not be where I am today had it not been for your dedication to completing your college education when Zach and I were just kids. While working two and three jobs to make sure we never went without, you persevered and your hard work paid off. Lastly, to my colleagues, thank you for being patient and allowing me to incessantly talk to you about my project, even if it was more than you anticipated. Thank you all for your encouragement along the way.

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Introduction and Background

Extracorporeal membrane oxygenation (ECMO) is one of the most complex and invasive rescue therapies for acute heart and/or lung failure (Tramm et al., 2014, p. 31). This mechanical system is used to temporarily rest the heart, lung, or both by providing full circulatory support and gas exchange (Tramm et al., 2014.). While the physical aspects of health-related quality of life (HRQOL) post ECMO have been reported, the psychological and emotional well-being of those who undergo ECMO for life-support has not been adequately studied.

Current evidence suggests that ECMO survivors have a high incidence of adverse mental health outcomes which contribute to poorer patient physical health, social functioning, and a decreased quality of life post critical illness (Tramm et al., 2014, p. 32). According to one study, the PTSD symptom burden was as high as 41% in long-term survivors of ECMO (Tramm et al., 2016, p. 221). This could have a further negative effect on these patients' functional status and quality of life. Despite this, the psychological and emotional aspects of care in this patient population often go under-treated both during and after their hospitalization, because the focus is on resolving the severe underlying condition that led to cardiac and/or respiratory failure. Therefore, identifying and managing PTSD symptoms in patients who undergo ECMO for acute heart and/or lung failure can potentially improve overall physical and mental well-being.

The Short Form 12 version 2 (SF12v2) Health Survey is a short form of the more traditionally used SF-36, has shown adequate validity and reliability, and is suitable for assessment of health status in numerous health-related conditions (Montazeri et al., 2011). The

SF12v2 takes approximately two minutes to complete and is a fast and efficient HRQOL screening tool that appears to be as effective as the original 36-question form. The ICU Memory Tool is validated and used to assess patients' memories of their ICU stay. Part A is given prior to discharge and consists of 8 questions that focus on their stay in the ICU, and take approximately five minutes to complete. Part B is given at the first follow-up and second follow-up visit (2-4 weeks and 12-16 weeks, respectively) post discharge. Part B consists of 14 questions about the patient's present-day thoughts and feelings, and takes approximately five minutes to complete.

Review of the Literature

Search methods for this synthesis of literature were conducted through the University of Kentucky library, which also includes access to PubMed and CINAHL; Google Scholar was also utilized. Search criteria were limited to full-text, peer reviewed English language articles within the last 10 years. Search terms included extracorporeal membrane oxygenation, ECMO complications and comorbidities; outcomes, ARDS OR heart attack, myocardial infarction, post cardiac arrest, VA ECMO, VV ECMO, adult, stress disorders, PTSD, post-traumatic stress disorders, depression, quality of life, cardiogenic shock, and respiratory distress syndrome. Articles included are in English, published within the past 10 years. Exclusion criteria were publication in a language other than English, publication prior to 2005. and a focus on pediatric patients. Of the two assisted searches through the CON and COM, approximately 121 articles were returned under the above criteria. Several articles were outside the timeframe, despite applied filters and were removed. The overall strength of the evidence was good and a revision to the search criteria was not warranted.

Current evidence suggests that extra-corporeal membrane oxygenation (ECMO) survivors have a high incidence of adverse mental health outcomes, which contribute to poorer patient physical health, social functioning, and a decreased quality of life post hospitalization. It is reasonable to assume that such intense and invasive medical approaches in life threatening situations, in conjunction with lengthened ICU stays does have an impact on these patients. These post-traumatic stress symptoms (PTSS) tend to manifest as post-traumatic stress disorder (PTSD) (Tramm et al., 2014; Tramm et al., 2016, p. 32). The memories of extremely stressful experiences in the ICU, invasive and traumatizing procedures, and delusional experiences could play a role in the development of PTSD or other mental health problems soon after discharge (Tramm et al., 2016; Tramm et al., 2014; Samuelson et al., 2007). Psychiatric co-morbidities such as anxiety and depression are commonly seen in this patient population; however they appear to be precursors to developing PTSD-like symptoms post ECMO hospitalization. It is interesting to note that the female sex, pessimism as a trait, memories of the ICU, and extreme fear during hospitalization are predictors for the development of high levels of acute PTSD-related symptoms (Samuelson et al., 2007;Castillo et al., 2012; Tramm et al., 2014; Combes et al., 2008; Risnes et al., 2013; Myhren et al., 2010).

Tramm et al., 2014, Tramm et al., 2016 and Davydow (2008) all suggest that experiences and LOS while in the ICU, prolonged sedation while on ECMO, and mechanical ventilation have a high prevalence of PTSD-like symptoms, anxiety, and depression that need to be further explored in this patient population once discharged. This cohort goes home from a lengthy ICU stay due to a critical diagnosis that led them to ECMO cannulation, and often leave with physical and cognitive deficits that keep them out of the workforce and/or from returning to

previous work levels for longer than expected (Davydow et al., 2008; Risnes et al., 2013). This cohort of patients are brought in from all over Kentucky and are essentially "treated and streeted" with no action plan in place to provide after-care from a holistic care perspective.

Current literature regarding post ECMO and HRQOL addresses their outcomes; however, there is a dearth of research to compare which diagnosis has a poorest outcome (respiratory, cardiac, or cardiopulmonary). Several studies have focused on complication rates, pre-operative risk factors, and survival as opposed to separating HRQOL out by diagnoses (Hsieh et al., 2016; Muller et al., 2016). Commonly identified quality of life issues post ECMO include decreased mobility, pain, memory difficulties, anxiety, and depression (Wang et al., 2017; McDonald et al., 2019; Roll et al., 2018). Roll et al. (2018) did examine 77 patients who received ECMO (45 veno-arterial and 32 veno-venous) and reported that of the two groups, 61% of participants who received VA-ECMO survived and 88% of participants who received VV-ECMO survived; however survival rates were based on the participants' age, comorbidities, and degree of organ dysfunction. Interestingly noted, Roll et al.(2018) pointed out that survival benefits linked to rehabilitation in ECMO patients have not been published and require further investigation.

While the literature highlights PTSD-like symptoms in patients with lengthy ICU stays, there is a gap in the literature regarding the patients who were subsequently placed on ECMO during their hospitalization, leading them to the ICU if they were not already there. To address lingering questions regarding PTSD-like symptoms and HRQOL post ECMO, our aim was to quantify the effect of ECMO on the psychological and emotional well-being in order to provide the necessary support needed both during and after hospitalization for successful

patient outcomes. Previous findings throughout the literature suggest that outpatient follow-up with these patients and early interventions and rehabilitation may allow for early identification of psychological and physical impairments to improve outcomes (Davydow et al., 2008; Myhren et al., 2010; Risnes et al., 2013; Combes et al., 2008; Hsieh et al., 2016; Wang et al., 2017; McDonald et al., 2019; Roll et al., 2018; Mirabel et al., 2011).

Purpose

The purpose of this study was to assess HRQOL and PTSD symptoms in ECMO survivors due to pulmonary and/or cardiac illnesses. The specific aims were to 1.) Assess the incidence of impaired quality of life and PTSD-like symptoms in survivors of ECMO; 2.) Identify which constellation of patients (respiratory vs. cardiac) have poorer HRQOL outcomes post ECMO; and 3.) Assess and compare the tools used (SF12v2 and ICUMT) to measure post procedural outcomes in this patient population. The expected outcomes for this project include identification of PTSD symptoms in ECMO survivors utilizing the ICUMT and SF-12v2 surveys and identification of the constellation of patients with poorer HRQOL post ECMO.

Measures and Instruments

The SF-12v2 Health Survey is a short form of the more traditionally used SF-36 and has shown to be a valuable tool when looking at a shift in overall health due to an intervention (Lefante et al., p. 672). It measures eight domains of health, which allows the provider to assess the physical and mental status of the target population. The SF-12v2 takes approximately two minutes to complete and is a fast and efficient HRQOL screening tool that appears to be as effective as the original 36-question form. The ICU Memory Tool is validated and used to assess patients' memories of their ICU stay. Part A is given at discharge, consists of

8 questions that focus on the patient's stay in the ICU, and takes approximately five minutes to complete. Part B is given at first follow-up (2-4 weeks) and second follow-up (12-16 weeks) post discharge; it consists of 14 questions about present day thoughts and feelings and also takes approximately five minutes to complete.

Theoretical Framework

This project utilized the Health Belief Model (HBM) as its theoretical framework. The HBM is based on a psychological and behavioral theory with the foundation that the two components of health-related behavior are 1) the desire to avoid illness, or get well if already ill; and, 2) the belief that a specific health action will prevent, or cure, illness (LaMorte, 2018, p. 1); specifically, the participants perceived severity of their illness and the perceived benefits of getting well.

Methods

Design

This was a prospective cohort study that was conducted prior to discharge, at the first and second follow-up visits (2-4 weeks and 12-16 weeks, respectively) post discharge.

Setting

The surveys were conducted at the University of Kentucky Hospital, which is a Level One Trauma Center. The sample for this study was comprised of patients admitted and discharged from PAV A 8th floor Tower 200 Cardiovascular ICU (CVICU). This is a 32-bed unit and the patient populations are managed predominately by the Cardiovascular and Cardio-thoracic Service lines. The CVICU has a specialized ECMO team that includes doctors, nurses, and perfusionists with the ability to retrieve patients from other facilities who have been placed on

ECMO, thus requiring a facility that can provide a higher level of care. A site-specific facilitator to the implementation of this project is that UKHC is designated as an ECMO Center of Excellence designated by the Extracorporeal Life Support Organization (ELSO). UKHC is also one of the few centers that offer a comprehensive program in extracorporeal life support (ECLS) for patients of all ages. Finally, UKHC is the only medical center in Kentucky to provide an adult ECMO transport service. Barriers to this project included cost, resource availability, and patient availability. UKHC is a regional facility that accepts patients from 9 different states in the Nation. It was important to assess the effect of HRQOL and PTSD-like symptoms in these patients post ECMO, due to the prevalence of these patients within the UK HealthCare system.

Sample

The target population selected for this study included those patients who were initially admitted between April 1, 2019 and October 31, 2019 who 1) had a respiratory and/or cardiac diagnosis and 2) were placed on ECMO during their stay and survived to discharge home. Recruitment began when notification ECMO cannulation was sent out. At that time, the investigator described the project to the patient and/or family. Each patient was followed throughout their stay until discharge, at which time, the investigator reintroduced the project to the patient and determined their willingness to participate. We initially aimed at recruiting 40 patients to participate in this study however, when the data collection time-point was close to an end we only had 5 participants. At that time, we extended out the data collection end date to December 31, 2019 in which we gained 2 more participants. We again extended out one more time to January 31, 2020 and gained one more participant. UKHC does has a large

volume of ECMO patients which is why the thought of 40 participants seemed feasible; it isn't putting patients on ECMO that is the difficult part, it's seeing them through to discharge due to the severity of their illness that led to ECMO in the first place.

We recruited 8 patients of varying demographic classification to participate in this project. We conveniently recruited participants, thus gender and ethnicity did not factor into who was asked to participate. Patient ages ranged from 18-99 years of age. Exclusion criteria included non-English speaking subjects or subjects from a foreign culture, and those younger than 18 years of age. The patient sample was pulled from the University of Kentucky Pav A 8th floor, 200 side CVICU. The CVICU is a 32-bed ICU that is the only unit within UK that accepts and manages ECMO patients.

Data Collection

Permission to administer the SF12v2 and ICUMT was obtained from the Institutional Review Board (IRB) and UK on March 18, 2019. Upon IRB approval, the CVICU manager and ECMO coordinator were contacted to discuss the DNP project and its goals. The unit manager and ECMO coordinator were encouraged to discuss the project and its aims to the CVICU staff members and the perfusion team and specialists. Emails to briefly discuss the project were also sent out to the CVICU staff members; to include the SF12v2 survey and ICUMT.

A waiver of documentation of consent was requested and obtained. Patients who met inclusion criteria between April 1, 2019 and January 31, 2020 were identified through a listserv sent out by the ECMO coordinator once VA and/or VV ECMO had been initiated. This along with the patient's chart were used to obtain the patients sex, age, race, comorbidity burden utilizing the Charlson Comorbidity Index

(https://www.thecalculator.co/health/Charlson-Comorbidity-Index-(CCI)-Calculator-765.html), location, LOS, ventilator days, and ECMO days. The information obtained from the listserv and chart was placed on a spreadsheet, all PHI was removed, and the chart information was assigned a study number. PHI was not collected on the ICUMT or the SF-12v2 health surveys. The surveys were administered to the patient by the principal investigator (PI), Julia Jones Akhtarekhavari, and/or Dr. Khaled Ziada prior to discharge, at the first follow-up visit (2-4 weeks), and again at the second follow-up visit (12-16 weeks). The initial survey was a paper survey given to the patient to fill out. Surveys given at first and second follow-up appointments post discharge were given either on paper at the patient's clinic visit or over the phone by the PI, Julia Jones Akhtarekhavari, and/or Dr. Khaled Ziada. The participants were made aware that it was all right not answer any questions that made them feel uncomfortable or to withdraw from the study at any time. The medical record number was placed on a separate file with the corresponding study number and housed on the PI's computer that was firewall and password protected and behind a locked door. The spreadsheet listed the medical record number and assigned numbers followed the UK Research policy and will be eliminated by the UK IT department overwriting the document at the end of the study. The data were extracted from these surveys to evaluate HRQOL and the prevalence of PTSD symptoms in ECMO survivors. Recruitment for this study concluded on January 31, 2020.

Data Analysis

Sample demographics were described using frequencies and percentages (categorical variables) and means and standard deviations (for continuous variables) (See Table 1). This was a prospective cohort study using summary measures and distributions to identify

HRQOL and symptoms of PTSD. Mean differences were tested using the two-sample t-test to compare respiratory vs cardiac diagnoses with the ICUMT and frequency distribution were used to test for the difference in HRQOL outcomes. Demographic differences in study participants with and without PTSD-like symptoms were also examined by using chi-square analysis (gender, ethnicity, and age). A one sample t-test was used to evaluate LOS, days on the ventilator, and days on ECMO. A Chi-square analysis was used to determine differences in HRQOL and PTSD symptoms. Statistician Amanda Thaxton-Wiggins assisted with data analysis.

Results

Population Demographics

The sample population included 74 patients who were placed on either VV and/or VA ECMO, of whom 42 that did not survive their hospital stay, 13 that declined to participate, 1 patient went home with hospice; 1 lacked the mental capacity to participate; and 9 were data collection only due to time constraints of the project. This left 8 patients who agreed to participate. The mean age for patients who required VA ECMO was 55.6. The mean age for patients requiring VV ECMO was 49.2, and 12.5% of males and 25% of females were placed on VA ECMO. Fifty percent of males and 12.5% of females were placed on VV ECMO (Table 2). Caucasian patients represented the largest ethnic group who were placed on either VA or VV ECMO 87.5%, followed by African Americans 12.5% (Table 1).

Sample Characteristics

The median length of stay (LOS) for patients requiring VV ECMO was 40.8 days (Table 1), while the median LOS for patients requiring VA ECMO was 26 days (Table 1). The most common respiratory diagnosis for patients requiring VV ECMO was acute respiratory distress syndrome (ARDS) at 40%, followed by respiratory failure at 40%. The most frequent cardiac diagnosis for patients requiring VA ECMO was cardiogenic shock secondary to a myocardial infarction at 66.7%, followed by aortic stenosis at 33.3%. The mean Charleson Comorbidity scale for those placed on VV ECMO was 2.8, and 3.6 for those placed on VA ECMO. The median time spent on a ventilator for those on VV ECMO was 12.4 days while those on VA ECMO were 10.3 (Table 1). Mean length on the ECMO circuit was 5.4 days for VV and 6 days for VA (Table 1).

Prevalence of PTSD symptoms

Part A of the ICUMT that was given at discharge consisted of 8 questions about the participants' memory of their time during their ICU stay (Table 2). Of the 8 participants, 62.5% did not recall being admitted to the ICU, nor did they remember the time leading up to admission to the ICU. While 62.5% remembered their time in the ICU, 57.1% stated that they could not clearly recall the stay; however, 62.5% clearly remembered their transfer out of the ICU to the floor. It is interesting to note that while 57.1% said they did not have feelings of panic or apprehension, 87.5% had intrusive memories from their hospital stay or event. Finally, when asked if they had discussed their hospitalization or event with anyone, 62.5% had spoken to family, while 25% spoke to a friend.

Some of the 8 main questions included follow-up questions for those who answered "yes" to the initial question. Question 4b asked what the patient remembered, and it was split into three categories of memories: factual memories, memories of feelings, and delusional memories (Table 3). Memories of feelings and factual memories were most prevalent at 87.5% and 62.5%, followed by delusional memories at 37.5%. Of the factual memories, family was most memorable followed by alarms, faces, the breathing tube, and a nasal tube. Of the memories of feelings, being uncomfortable and in pain were most memorable followed by confusion. Of delusional memories, dreams were most common followed by nightmares. Question 4c of the ICUMT asked "If you had any feelings that someone was trying to hurt or harm you while in the ICU can you please describe these feelings." Not all participants answered; however one stated "I had dreams someone was trying to kill me" (Table 4). Question 4d asked, "If you had nightmares or hallucinations while you were in the ICU could you please describe these?" One participant stated, "I don't like being in the dark," while one recalled "dreams about holidays and food" (Table 4). Question 6 asked whether the patient had any feelings of apprehension or panic, and 6a asked those who responded affirmatively to describe what they were doing when those feelings occurred. One respondent did not remember, despite answering yes to question 6, and one patient said "being moved up in the bed thinking I was going to fall off the bed" (Table 4). Question 7 asked if the patient had any intrusive memories from their time in the hospital, but those who responded yes did not provide a response to questions 7a or 7b (Table 4).

At the second and third data collection time points, the ICUMT Part A consisted of four questions that asked the patient to think back to the time of their severe illness and the time

spent in the ICU and asked if they had experienced any nightmares, severe anxiety or panic, severe pain, or trouble breathing/feelings of suffocation. Nightmares were prevalent in 66.7% of the respondents at the first follow-up time point (2-4 weeks post discharge), however they disappeared by the second follow-up time point (12-16 weeks post discharge; Table 5). Severe anxiety or panic were less prevalent at the first time point (16.7%), but increased to 33.3% at the second time point (Table 5). Severe pain and trouble breathing/feelings of suffocation were less prevalent at the first follow-up time point (33.3%) and stayed consistent at the second follow-up time point (Table 5). Part B of the second and third survey consisted of 14 questions on a 7-point Likert scale. At the first follow-up time point (2-4 weeks post discharge) a mean score of 22.5 with a standard deviation of 11.4 was present and for the second follow-up time point (12-16 weeks post discharge) a mean score of 19.0 with a standard deviation of 7.8 was present (Table 5). The scoring range for part B was 10-98 points; the higher the score the greater the prevalence of PTSD symptoms. Scores were relatively low in this study.

The mental component score (MCS) portion of the SF12v2 looked at the mental well-being aspect of the participants HRQOL in comparison to the general population. At discharge, 57% of participants felt that their mental health was the same or better compared to the general population, and this stayed consistent at their first follow-up appointment (2-4 weeks post discharge) and second follow-up appointment (12-16 weeks post discharge; Table 6). Breaking it down by diagnosis, 80% of those with a respiratory diagnosis felt that they were the same or better at time of discharge. This dipped slightly to 50% at the first follow-up appointment and rose back up at 100% at the second follow-up appointment (Table 7). Those

participants with a cardiac diagnosis felt their mental well-being was well below that of the general population (100%), however this seemed to resolve at their first follow-up appointment, where they all stated their mental well-being was the same or better than that of the general population (Table 7). It is interesting to note here that the ICUMT and the MCS aspect of the SF12v2 appear to have similar results; while they initially appeared to score low upon discharge, those feelings seemed to resolve by the first and second follow-up appointments.

Prevalence of poor HRQOL

The physical component score (PCS) of the SF12v2 refers to the physical aspect of the participants' HRQOL as compared to the general population. At discharge as a whole, 57.1% of participants felt that their physical health was well below that of the general population, however at their first follow-up appointment (2-4 weeks post discharge) only 33.3% felt they were still well below that threshold. At the second follow-up appointment (12-16 weeks post discharge) 66.7% of participants felt their physical health was well below that of the general population (Table 6). Breaking this down by diagnosis, the physical component summary (PCS) score for those who had a respiratory diagnosis at discharge, HRQOL was the same or better compared to the general population, however declined slightly at the first and second follow-up appointments. PCS for those who had a cardiac diagnosis, HRQOL was well below at discharge at 100%; however, it rose to below the general population at the first follow-up appointment. Those with a respiratory diagnosis did better at discharge, but their physical health steadily declined at the first and second follow up appointments. In contrast, those with a cardiac diagnosis all felt well below average in physical health at discharge, and they all rose to below

in physical health at their first follow-up. There was no comparison at the second follow-up appointment, as all three of the participants who completed all three surveys, all which had a respiratory diagnosis.

Discussion

This exploratory study was designed to gather information, therefore no alternate intervention was implied. We wanted to assess the incidence of impaired QOL and PTSD-like symptoms in survivors of ECMO. Looking at the overall results of the SF12v2, 12% of participants were well below the general population for both MCS and PCS. Less than half (42.9%) were well below for MCS at discharge and remained through the first follow-up appointment, however this resolved by the second follow-up appointment. It was interesting to note that while the MCS scores steadily increased from time of discharge, the PCS steadily declined. If depression and/or PTSD-like symptoms are more prevalent at discharge in this patient population, this raises important questions about whether this may be related to some aspect of the discharge process itself. For example, it is possible that there are patients who are about to go home from the hospital after a serious illness or injury may experience significant fear. This is something that we as clinicians should look at further to better prepare this patient population during their stay and through to discharge to ensure a smoother transition to home with less anxiety about what is to come.

The second aim was to identify which constellation of patients (respiratory vs cardiac) had poorer HRQOL outcomes post ECMO. VV ECMO patients typically had a longer LOS and more ventilator days compared to VA ECMO however; VA ECMO patients tend to be more critically ill due to the severity of their acute illness. VV ECMO tends to be used for respiratory

failure related to acute respiratory distress syndrome (ARDS) or pneumonia, unless the patient is waiting for a transplant. When managing VA ECMO, the goal is to offload the heart to reach the point of decannulation, so there is a lot that clinicians can do to alter the hemodynamics of the heart (e.g. medications). When it comes to the lungs, there really isn't anything clinicians can do to assist in the process. For PCS, less than half of the patients with respiratory diagnoses fell in the well below category at discharge (40%), compared to 100% of the cardiac diagnosis patients. At the first and second follow-up appointments, those with a respiratory diagnosis increased to 66.7% while 100% of the cardiac diagnosis patients felt they were below the general population in physical health (Table 7). For respiratory MCS only 20% were well below at discharge compared to 100% of the cardiac patients. While there were no statistically significant differences between the groups, anecdotally cardiac patients are more at risk than respiratory patients due to the severity of their acute illness.

The third aim was to assess and compare the tools used (SF12v2 and ICUMT) to measure post procedural outcomes in this patient population. While the ICUMT did not necessarily have a physical component, the MCS aspect of the SF12v2 and the ICUMT results appeared to align with one another. The ICUMT part B for the second and third survey Likert scale had relatively low mean scores (22.5/SD 11.4 and 19.0/SD 7.8). The MCS aspect of the SF12v2 had less than half that were well below the general population at discharge, but by data point three, all were the same or better.

Overall, the incidence of impaired HRQOL and PTSD-like symptoms were increased on discharge. However, overtime PTSD-like symptoms decreased. Patients admitted with a cardiac

diagnosis had poorer overall outcomes compared to their respiratory counterparts. Supportive services during hospitalization would greatly benefit this patient population.

Implications for Practice and Future Research

This study may be used to support future research in several ways. One possibility would be to initiate a palliative care consult within 4 to 7 days of ECMO initiation. ECMO is meant to be short-term, as a bridge to transplant or left ventricular assist device (LVAD) implementation. Around the 4 to 7-day mark, providers should be able to determine where the plan of care for the patient is headed. The difficulty with palliative care is getting providers to recognize that a palliative consult is not a hospice consult. More provider education is needed in this area because patients can greatly benefit from palliative medicine. This can ultimately lead to patient empowerment in their care and decreased hospital admissions in the future. Another possibility would be to create a "track and trigger" within the charting system for this patient population once they are decannulated from ECMO. This could involve a complementary medicine consult such as mindfulness, narrative medicine, or a psych consult to provide mental health support. Another implication is the decision to cannulate a patient for ECMO. Currently the decision is placed on one physician, which can be daunting. It would be beneficial to place the decision to cannulate on the ICU attending and the physician cannulating the patient to ensure there is an agreement that ECMO cannulation is in fact the right decision, and there is a plan for ECMO decannulation in sight.

This study has brought to light several implications for future research. This study was a performed at the University of Kentucky (single-center). Doing this as a multi-facility study would generate a larger cohort of participants for data. It would be interesting to look at the

rate of ECMO initiation after implementation of the two-physician agreement; researchers could also look at the rates of ECMO initiation and compare outcomes with two-physician consents. One last implication for future research would be to examine cannulation via interventionalist vs cardiothoracic surgeon and patient outcomes and complication rates. Serendipitous findings would be looking into a quarterly cost analysis that looks at cannulation site in relationship to reimbursement (e.g. bedside ECMO cannulation pays more than ECMO cannulation in the Cath Lab or OR). This would obviously need to be looked at more in depth to ensure patient risks and outcomes are the same.

Limitations

Several limitations were noted during the course of this study. This was a single-center design with a small sample size despite extending our data collection timeframe two times, and this limits generalizability. Patients were difficult to contact after their hospitalization due to disconnected phone numbers, wrong phone numbers, and cancelled patient appointments. Of the 74 patients who were placed on ECMO during the data collection period, 42 patients expired due to their illness; that equals 56.7% of the potential patients. Most notably, there has been a lot of data collection around PTSD related to ICU stay, however for this study, there is no way to know if the patient's PTSD symptoms are related to being placed on ECMO, or their time spent in the ICU due to their illness. One final note, after hospitalization, these patients are physically and mentally exhausted. Throughout the course of their stay these patients have been asked over and over to participate in aspects related to their care. They have had enough stressors during their stay. It has been proven that patients experience fatigue related to continuous expectations for participation in care activities as well

as evaluation protocols, so any added expectations for this particular patient population could come across overwhelmingly as well as an additional stressor.

Conclusion

The purpose of this study was to assess HRQOL and PTSD-symptoms in ECMO survivors due to a pulmonary and/or cardiac illness. Overall, the incidence of impaired HRQOL were found to be increased while PTSD-like symptoms were initially increased and subsequently decreased for the patient population in this study. Those patients who were admitted with a cardiac diagnosis had poorer outcomes than those admitted with a respiratory diagnosis post ECMO. Despite overall scores, study results did not show any statistical changes. Further studies are recommended to evaluate patient mental well-being on a larger multi-center scale which may alter the results obtained in this study. Evidence is overwhelming that support services are beneficial for this patient population to enhance both physical and mental well-being during and after their hospitalization, with an increased focus on their physical well-being.

Table 1

Descriptive Sample Table (n=8)

	N (%)		
Sex		Mean Age TTL	8 (51.6 years)
Male	5 (62.5%)	VA	3 (55.6 years)
Female	3 (37.5%)	VV	5 (49.2 years)
Race		Mean LOS TTL	8 (35.3 days)
African American	1 (12.5%)	VA	3 (26 days)
Caucasian	7 (87.5%)	VV	5 (40.8 days)
Diagnosis		Mean Vent Days TTL	8 (11.6 days)
Respiratory	5 (62.5%)	VA	3 (10.3 days)
Cardiac	3 (37.5%)	VV	5 (12.4 days)
ECMO type		Mean ECMO Days	
VA	5 (62.5%)	VA	3 (6 days)
VV	3 (37.5%)	VV	5 (5.4 days)

Table 2

Descriptive Summary of Patient's ICU Memory Part A (n=8)

Part A at discharge	*n* (%)	Part A at discharge	*n (%)*
Patient type		Transfer to floor	
Respiratory	5 (62.5%)	remembered	
Cardiac	3 (37.5%)	Clearly	5 (62.5%)
		Hazily	1 (12.5%)
		Not at all	2 (25.0%)
Remember being		Feelings of	
admitted	2 (25.0%)	panic/apprehension	
clearly	1 (12.5%)	Yes	3 (42.8%)
hazily	5 (62.5%)	No	4 (57.1%)
not at all			
Time before ICU admit		Intrusive memories from	
All of it	2 (25.0%)	hospital or event	
Some of it	1 (12.5%)	Yes	1 (12.5%)
Nothing	5 (62.5%)	No	7 (87.5%)
Do you remember the ICU		Talked about incident with:	
Yes	5 (62.5%)	Family	5 (62.5%)
No	3 (37.5%)	Nurse	1 (12.5%)
		Friend	2 (25.0%)
		Doctor	0 (0%)
		Family doctor	0 (0%)
Stay clearly remembered			
Yes	3 (42.8%)		
No	4 (57.1%)		

Table 3 *Question 4b ICUMT Given at Discharge*	
What do you remember?	n=8 (%)
Factual memories Family, alarms, voices, lights, faces, breathing tube, suctioning, darkness, clock, tube in nose, ward round	5(62.5%)
Memories of feelings Being uncomfortable, feeling confused, feeling down, feeling anxious/frightened, panic, pain	7 (87.5%)
Delusional memories Feeling that people were trying to hurt you, hallucinations, nightmares, dreams	3 (37.5%)

Table 4

ICUMT 4c, 4d, 6a, 7a, & 7b

Question	Summarized Patient Responses
4c. If you had any feelings that someone was trying to hurt or harm you while in ICU can you, please describe these feelings.	- *"no"* - *"I had dreams someone was trying to kill me"* - *"Didn't feel that way"*
4d. If you had nightmares or hallucinations while you were in ICU could you please describe these.	- *"Don't like to be in the dark"* - *"None"* - *"Dreams about holidays and food"*
6a. *If yes:* What were you doing when these feelings happened?	- *"I don't remember"* - *"Being moved up in the bed, thinking I was going to fall off the bed"* - *"Laying around"*
7a. *If yes to 7:* What were you doing when these intrusive memories happened?	No response
7b. *If yes to 7:* What did these memories consist of (e.g. frightening nightmares)?	No response

Table 5

Comparison of ICUMT Part A and B of Second/Third Survey

	2-4 weeks post discharge		12-16 weeks post discharge	
Part A	% responded yes	% responded no	% responded yes	% responded no
Nightmares	66.7%	33.3%	0%	100%
Severe anxiety or panic	16.7%	83.3%	33.3%	66.7%
Severe Pain	33.3%	66.7%	33.3%	66.7%
Trouble to breath/feelings of suffocation	33.3%	66.7%	33.3%	66.7%
Part B	Mean (SD)		Mean (SD)	
Total (potential 10-98)	22.5 (11.4)		19.0 (7.8)	

Table 6

ECMO Survivor HRQOL Compared to General Population

	Discharge (n=7) %	2-4-week post discharge (n=6) %	12-16 weeks post discharge (n=3) %
Physical			
Same or better	42.9%	33.3%	33.3%
Below	0.0%	33.3%	0.0%
Well below	57.1%	33.3%	66.7%
Mental			
Same or better	57.1%	50.0%	100%
Below	0%	33.3%	0%
Well below	42.9	16.7%	0%

Table 7

ECMO Survivor HRQOL Outcomes by Diagnosis Compared to the General Population

	Respiratory			Cardiac		
	Discharge (n = 5)	2-4 (n=4)	12-16 (n=3)	Discharge (n=2)	2-4	12-16
Physical						
Same or better	60.0%	50.0%	33.3%	0.0%	0%	0%
Below	0.0%	0%	0%	0.0%	100%	0%
Well below	40.0%	50.0%	66.7%	100.0%	0%	0%
Mental						
Same of better	80.0%	25.0%	100%	0%	100%	0%
Below	0%	50.0%	0%	0%	0%	0%
Well below	20.0%	25.0%	0%	100%	0%	0%

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