

**An exploration of staff experiences of  
extracorporeal membrane oxygenation (ECMO)**

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## TABLE OF CONTENTS

<b>ABSTRACT</b> .....	9
<b>1. INTRODUCTION</b> .....	10
<b>1.1. A Brief Introduction to Intensive Care Medicine</b> .....	10
<b>1.2. Challenges for Doctors and Nurses Working in an Intensive Care Unit</b> .....	10
1.2.1. <u>Structural Challenges</u> .....	11
1.2.2. <u>Practical Considerations in Direct Patient Care</u> .....	12
1.2.2.1. <i>Technological implications for patient care</i> .....	12
1.2.2.2. <i>Communicating with patients</i> .....	13
1.2.3. <u>Intersection of Moral, Ethical and Professional Issues in the ICU</u> .....	14
1.2.3.1. <i>Decision-making on behalf of patients</i> .....	14
1.2.3.2. <i>Communicating with relatives</i> .....	14
1.2.3.3. <i>Professional status, power and decision-making</i> .....	15
1.2.3.4. <i>Ethical decisions and moral distress</i> .....	16
1.2.3.5. <i>Challenges in end-of-life-care</i> .....	16
1.2.4. <u>The Impact of Working in Intensive Care</u> .....	17
1.2.4.1. <i>Burnout syndrome</i> .....	17
1.2.4.2. <i>Compassion fatigue</i> .....	18
1.2.4.3. <i>Mental health</i> .....	18
1.2.5. <u>Protective Practices and Processes</u> .....	18
<b>1.3. The Challenges of Intensive Care Work and Advanced Technology</b> .....	19
<b>1.4. An Introduction to ECMO</b> .....	20
1.4.1. <u>'Varieties' of ECMO</u> .....	20

1.4.2. <u>Broad Uses and Benefits of ECMO</u> .....	21
1.4.3. <u>Specialist Care Practices</u> .....	21
1.4.4. <u>ECMO Retrieval</u> .....	22
1.4.5. <u>Evidence Base and Complications</u> .....	22
1.4.6. <u>Experiences of ECMO Care</u> .....	23
<b>1.5. Systematic Literature Search</b> .....	23
1.5.1. <u>Phase One: Selecting Search Criteria</u> .....	24
1.5.1.1. <i>Database selection</i> .....	24
1.5.1.2. <i>Identification of key search terms</i> .....	24
1.5.2. <u>Phase Two: The Process of Conducting the Literature Search</u> .....	25
1.5.2.1. <i>Searches derived from thesauri and major subject headings: EBSCO</i> .....	25
1.5.2.2. <i>Searches derived from free-text and Boolean phrases</i> .....	26
1.5.2.3. <i>Included and excluded articles</i> .....	26
<b>1.6. Findings of Systematic Literature Search</b> .....	27
<b>1.7. Challenges of Working with ECMO</b> .....	27
1.7.1. <u>Professional and Ethical Challenges of Working with ECMO</u> .....	27
1.7.1.1. <i>Cost vs. benefit</i> .....	27
1.7.1.2. <i>Initiating ECMO</i> .....	28
1.7.1.3. <i>End-of-life and withdrawal of ECMO</i> .....	29
1.7.1.4. <i>ECPR, do not resuscitate (DNR) and ECMO</i> .....	30
1.7.1.5. <i>The 'bridge to nowhere'</i> .....	31
1.7.1.6. <i>ECMO and organ donation</i> .....	31
1.7.1.7. <i>Communicating with patients and families</i> .....	31
1.7.2. <u>Impact on Staff Working Practices</u> .....	32

1.7.2.1. <i>Staffing pressures during high ECMO demand</i> .....	32
1.7.2.2. <i>Challenges of ECMO retrieval</i> .....	32
1.7.2.3. <i>Training, education and practice</i> .....	33
1.7.3. <u>Impact on Staff Well-Being</u> .....	34
1.7.3.1. <i>Detrimental impact on well-being</i> .....	34
1.7.3.2. <i>Mitigating interventions</i> .....	34
1.7.3.3. <i>Positive experiences</i> .....	35
1.7.4. <u>Rationale, Purpose and Aims of this Research</u> .....	35
<b>1.8. Research Questions</b> .....	36
<b>2. METHODOLOGY</b> .....	37
2.1. <b>Epistemology</b> .....	37
2.2. <b>Design</b> .....	38
2.3. <b>Ethical Approval</b> .....	39
2.3.1. <u>Research and Development Approval and Indemnity</u> .....	39
2.4. <b>Participants</b> .....	40
2.4.1. <u>Recruitment Context and Details of the ECMO Service</u> .....	40
2.4.1.1. <i>Details of the service model</i> .....	40
2.4.1.2. <i>Positioning of the researcher in the organisational context</i> ...	40
2.4.2. <u>Sampling and Recruitment Strategy</u> .....	41
2.4.2.1. <i>Inclusion/exclusion criteria</i> .....	41
2.4.3. <u>Recruitment Process: Snowball Sampling</u> .....	42
2.4.3.1. <i>Establishing conceptual depth</i> .....	43
<b>2.5. Data Collection Procedure</b> .....	43
2.5.1. <u>Obtaining Consent and Demographic Data</u> .....	43
2.5.1.1. <i>Confidentiality, anonymity and dissemination</i> .....	43

2.5.1.2. <i>Collection of demographic data</i> .....	44
2.5.2. <u>Other Interview Preparations</u> .....	44
2.5.2.1. <i>Development of interview schedule</i> .....	44
2.5.2.2. <i>Overview of key research resources</i> .....	44
2.5.2.3. <i>Research supervision</i> .....	44
2.5.2.4. <i>Interview locations</i> .....	44
2.5.3. <u>Secure Storage of Data</u> .....	45
2.5.4. <u>Structure and Process of Interviewing</u> .....	45
2.5.5. <u>Interview Debrief</u> .....	46
2.5.6. <u>Participant Demography</u> .....	46
<b>2.6. Data Analysis</b> .....	47
2.6.1. <u>Transcription</u> .....	47
2.6.2. <u>Data Analysis Procedure</u> .....	48
<b>2.7. Establishing Credibility of Data Collection and Analysis</b> .....	50
2.7.1. <u>Consistency of Data Collection and Analysis</u> .....	50
2.7.1.1. <i>Consistency in data collection</i> ... ..	50
2.7.1.2. <i>Consistency in data analysis</i> .....	51
2.7.1.3. <i>Truth-value of findings</i> .....	51
<b>3. RESULTS</b> .....	52
<b>3.1. Embodying the ECMO Specialist</b> .....	53
3.1.1. <u>The Paradox of Feeling Masterful and Inept</u> .....	53
3.1.2. <u>Learning and Development</u> .....	57
3.1.3. <u>Professional Drive and Personal Sacrifice</u> .....	59
<b>3.2. Team Dynamics</b> .....	60

3.2.1. <u>Team Spirit</u> .....	60
3.2.2. <u>The Divisive Nature of ECMO</u> .....	64
<b>3.3. Riding the Emotional Rollercoaster</b> .....	67
3.3.1. <u>Extremes of Life, Death and Emotion</u> .....	68
3.3.2. <u>Managing Emotions</u> .....	72
<b>4. DISCUSSION</b> .....	77
<b>4.1. Main Findings</b> .....	77
4.1.1. <u>Adapting to Differing Conceptual Frameworks</u> .....	78
4.1.1.1. <i>Adapting to a Framework of Added Technical and Clinical Responsibility</i> .....	78
4.1.1.2. <i>Adapting to an Ethical and Human Framework</i> .....	79
4.1.2. <u>Psychological Management in a Context of High Emotion</u> .....	81
4.1.2.1. <i>Defenses against Moral Distress and High Emotion</i> .....	81
4.1.2.2. <i>Professional status, power and emotional expression</i> .....	83
4.1.3. <u>Consequences of the Drive to Achieve Greatness with ECMO</u> ...	84
4.1.4. <u>Relationship with Technology</u> .....	85
4.1.5. <u>Summary of Findings in Relation to Research Questions</u> .....	87
<b>4.2. Implications for Clinical Practice</b> .....	88
4.2.1. <u>Encouraging Teamwork and Preventing Division</u> .....	88
4.2.2. <u>Developing Skills in the Communication of Sensitive Information to Relatives</u> .....	88
4.2.3. <u>Utility of Understanding Protective and Defensive Practices</u> .....	89
4.2.4. <u>Setting up Appropriate Support Systems for Staff</u> .....	89
<b>4.3. Critical Review</b> .....	90
4.3.1. <u>General Research Limitations</u> .....	91
4.3.2. <u>Reflections on the Research Process</u> .....	91

4.3.2.1. <i>Recruitment challenges</i> .....	91
4.3.2.2. <i>Impact of ability, language, professional status and power on the interview process</i> .....	92
4.3.2.3. <i>Impact of gender and physical stature on the interview process</i> .....	93
4.3.2.4. <i>Impact of professional status on research methodology</i> .....	93
4.3.3. <u>Appraisal of Research Quality</u> .....	94
4.3.3.1. <i>Adequacy of design and data collection</i> .....	94
4.3.3.2. <i>Reflexive and ethical considerations</i> .....	95
4.3.3.3. <i>Rigour of analysis</i> .....	95
4.3.3.4. <i>Statement of findings</i> .....	95
4.3.3.5. <i>Value of the research</i> .....	96
4.3.3.6. <i>Critique of quality assessment</i> .....	96
<b>4.4. Dissemination and Considerations for Future Research</b> .....	96
<b>4.5. Concluding Remarks</b> .....	97
<b>5. REFERENCES</b> .....	99
<b>6. APPENDICES</b> .....	135
6.1. <b>Appendix A – Systematic Literature Search Terms</b> .....	135
6.2. <b>Appendix B – Ethics Review Decision Letter</b> .....	148
6.3. <b>Appendix C - Health Research Authority Approval Notification</b> .....	151
6.4. <b>Appendix D – Letter of Indemnity and Sponsorship</b> .....	152
6.5. <b>Appendix E – Initial Email to Potential Participants</b> .....	153
6.6. <b>Appendix F – Description of Conceptual Depth Criteria and their Application to this Research</b> .....	154

<b>6.7. Appendix G – Participant Information Sheet.....</b>	<b>155</b>
<b>6.8. Appendix H – Participant Demographic Form.....</b>	<b>158</b>
<b>6.9. Appendix I – Participant Demographic Form.....</b>	<b>159</b>
<b>6.10. Appendix J – Interview Schedule.....</b>	<b>161</b>
<b>6.11. Appendix K – Interview Debrief Form.....</b>	<b>163</b>
<b>6.12. Appendix L – Example of Coding from Original Data Corpus.....</b>	<b>164</b>
<b>6.13. Appendix M – Example of Coding Frame.....</b>	<b>165</b>
<b>6.14. Appendix N – Thematic Maps Explaining Thematic Development.....</b>	<b>166</b>

## TABLE OF FIGURES AND TABLES

Table i - Relevant major search terms, synonyms and other related terms used as a basis for literature searching.....	25
Table ii - A breakdown of participants' ethnicity and professional grade/job role.....	47
Table iii - A Breakdown of Superordinate Themes and their Component Subthemes.....	52
Table iv - Systematic literature search findings: Number of articles identified in thesaurus and free text Boolean searches within different academic databases.....	135
Figure i - Broad code groupings after initial coding of data.....	166
Figure ii - Interim thematic map following grouping of codes.....	166
Figure iii - Final thematic map.....	167



**ABSTRACT**

Intensive care unit (ICU) staff are exposed to a broad range of professional, ethical and clinical practice issues such as when to offer and withdraw potentially life-saving care, which are most apparent when working with hyper-advanced technologies such as extracorporeal membrane oxygenation (ECMO). Despite the rapid increase in use of ECMO to support adults with critical heart and lung conditions, few studies have documented staff experiences of working with this technology. This study aimed to explore ICU doctors and nurses conceptualisations of key professional, ethical and clinical practice issues relating to ECMO, and the psychological impact of managing them.

A qualitative design was utilised, in which semi-structured interviews were conducted with 10 ICU staff (five doctors and five nurses), working in a specialist ECMO centre in the United Kingdom (UK). Data were analysed using thematic analysis, underpinned by a critical realist epistemological stance. Three key themes were identified. 1) Embodying the ECMO Specialist: Staff experienced a sense of mastery when managing technical aspects of the work, but felt inept when dealing with abstract ethical issues. Specialists sought to drive forward clinical practice, and learning was considered important for developing clinical abilities. 2) Team dynamics: Staff came together as a team to address the technical, professional and ethical challenges associated with their work with ECMO, however ECMO was also described as a divisive force in the ICU. 3) Riding the Emotional Rollercoaster: Life or death outcomes were associated with intense emotions and staff reported various ways of managing them.

These findings add a new dimension to the professional and ethical discussions in the academic literature and have several implications for clinical practice, which are discussed. Further research may wish to focus on more specific aspects of ECMO care, such as the processes involved in decision-making.

## **1. INTRODUCTION**

### **1.1. A Brief Introduction to Intensive Care Medicine**

Intensive care units (ICUs) or critical care units appeared in the United Kingdom (UK) in the early 1960's, offering high quality care to patients with critical illnesses. Treatment in the ICU often involves complex machinery and is carried out by highly trained staff, whose goal is to support the basic functions of the human body and facilitate recovery (Robinson, 1966; Vincent, 2013). Common reasons for ICU admission and treatment include life-threatening conditions such as cardiac, respiratory and renal failure (Danbury et al., 2013; Robinson, 1966). ICUs are generally stand-alone wards separated from the rest of the hospital and contain their own multidisciplinary teams (MDT's) (Danbury et al., 2013). Contemporary ICU treatment aims to utilise technological advances in medical equipment and treatments, in order to save lives, provide humane care, promote recovery and facilitate comfortable end-of-life care (Vincent, 2013).

### **1.2. Challenges for Doctors and Nurses Working in an Intensive Care Unit**

Staff may be drawn to work in ICUs in order to work with highly skilled professionals and cutting edge technology, care for the most physically ill individuals and their relatives and develop specialist expertise that can be applied to reduce suffering and save lives (Cottrell & Kendall, 2010; Wahlin, Ek & Idvall, 2010). However, ICUs are renowned for being challenging places to work and it is therefore no surprise that the academic literature in this area is replete with articles discussing the challenges, as opposed to the positives of ICU work.

The writings of ICU professionals such as Dannenfeldt (1982) and Eisendrath and Dunkel (1979) have highlighted some of the key challenges of working within this setting, including: substantial clinical responsibilities, high workload and pressure to perform 'clinical wonders' within the context of resource limitations. Tensions can exist within and between professional groups, as a result of communication difficulties and differing professional perspectives, priorities and

practices. Buxman (2000) also notes difficult structural and professional aspects such as: high staff turnover, poor work/life balance, treating patients with poor prognoses, and keeping knowledge and skills up-to-date to operate sophisticated technologies. These challenges vary in frequency and intensity between differing professional groups and ICUs. In addition, individuals and teams may respond to these challenges in very different ways (Coomber et al., 2002).

The first portion of this literature review will focus in greater detail, on the general demands of working in an ICU setting and the impact on staff, which will then be used to guide specific discussions in relation to the focus of this thesis, extracorporeal membrane oxygenation (ECMO). The challenges of ICU work will be considered in greater detail, alongside the psychological impact on staff and protective factors and positive aspects of the work. Doctors and nurses are the two largest professional groups working in this setting and as such, have been the focus of much research in this area. Therefore, the literature below focuses primarily on these professional groups, which also have most relevance to the participants recruited for this research.

#### 1.2.1. Structural Challenges

The smooth running of an ICU involves a range of structural challenges. Staffing resources must be managed in order to meet the needs of patients and high demand for services, including the adaptation of staff working practices. However, this may have a detrimental impact on the well-being of ICU professionals.

Shift working and overtime are common working conditions for clinicians on ICUs and can contribute to fatigue, which impacts productivity and cognitive abilities (e.g. decision-making), and potentially patient safety (Argent, Benbenishty & Flaatten, 2015). Richardson, Turnock, Harris, Finley and Carson (2007) found that ICU nurses working long 12-hour shifts could cope with extended working patterns, as long they were well planned. Benefits included having more time for patients and relatives, spreading out workload and increased quality-of-life outside of work. However, nurses in this study commented that they were more likely to become fatigued when they worked for too many consecutive days. A

more recent large-scale study of nurses across Europe found that 12-hour shifts were associated with higher rates of burnout and reduced job-satisfaction (Dall'Ora, Griffiths, Ball, Simon & Aiken, 2015).

Physicians are said to be able to cope with long shifts, providing they have regular days off in which to recover (Embracio et al., 2012). However, irregular shift patterns including night-shifts, can impact cognitive performance and raise the risk of clinical error, reportedly a common problem in ICUs (Maltese et al., 2016). Errors affect a large proportion of ICU patients and lead to poorer clinical outcomes, or even death (Moyen, Camire & Stelfox, 2008).

Low-staffing levels can result in nurses having difficulty completing essential tasks, impacting the quality of patient care (Ball, Murrells, Rafferty, Morrow & Griffiths, 2013). In the ICU setting, time, resource and staffing constraints make it difficult for nurses to care for patients effectively and carry out the treatment decisions made by doctors and the broader MDT (Bucknall & Thomas, 1997). It can also result in increased levels of anxiety (McHenry, 1981). Regulatory bodies for both physicians and nurses have set minimum staffing/resource standards and working conditions for ICUs, with a focus on maintaining patient safety and high quality care (Danbury et al., 2013; Galley & O'Riordan, 2003; Valentin & Ferdinande, 2011). However, the increasing demand for resources may make it difficult to sustain these standards (Courtright & Kerlin, 2014).

#### 1.2.2. Practical Considerations in Direct Patient Care

Clinicians working in the intensive care environment are required to adapt their clinical practice to accommodate patients who have difficulty communicating, are incapacitated or are attached to life saving machinery. These adaptations can be beneficial, but may also pose challenges for patient care.

1.2.2.1. *Technological implications for patient care*: Intensive care work involves the use of complex machinery to monitor, treat and care for patients. This technology has evolved over time to increase patients' quality-of-life and care, and their chances of survival (Puri, Puri & Dellinger, 2009). A small body of literature has considered staff experiences of working with such technology.

Tunlind, Granstrom and Engstrom's (2015) interviews with Swedish ICU nurses revealed that technology had both positive and negative implications for their work. Advances in medical equipment made nursing tasks such as personal care, extracting bodily fluids or administering medications quicker and easier to carry out, and provided reassurance to staff that complex physical care and treatment was being conducted safely. Similarly, Alasad (2002) found that the idea of machinery monitoring patients' vital signs provided ICU nurses with a sense of reassurance that the patient was safe and well.

Despite the benefits of high technology in ICUs, some nurses have suggested that from a practical standpoint, medical equipment can impede physical care tasks like moving and washing, resulting in the need to adapt traditional approaches to care (Tunlind et al., 2015). In addition, medical equipment is prone to malfunction, and ICU nurses may feel a sense of responsibility for this, attributing blame for negative outcomes to themselves (Haghenbeck, 2005). Newly trained nurses can find using technology to be anxiety provoking and leave them feeling de-skilled. Some have described needing to 'face their fears' and gain a better understanding of medical equipment, in order to experience a sense of mastery and use it to benefit the patient (Alasad, 2002; Silva & Ferreira; 2011). Thus, greater experience may result in feelings of competence and confidence (Alasad, 2002). However, the introduction of new equipment can result in such anxieties resurfacing, and a lack of familiarity can reduce the amount of time focused on patient care (Tunlind et al., 2015). Even experienced ICU nurses report having difficulty sustaining the knowledge required to treat patients with new technologies, given their rapid proliferation (Bucknall & Thomas, 1997; Puri et al., 2009).

1.2.2.2. *Communicating with Patients*: Patient communication also presents a key challenge to ICU staff. Happ et al. (2011) have suggested that conscious ICU patients often have difficulty communicating their needs because of cognitive impairment, lethargy and insertion of tubes into their throat. As a result, around a quarter of nurse-patient interactions can end up being unsuccessful. Patients may require additional support to communicate their needs and staff may have to interpret their use of gestures, lip-read or utilise a communication board. These

are time consuming practices and can be frustrating for all communicating parties.

### 1.2.3. Intersection of Moral, Ethical and Professional Issues in the ICU

Clinical practice in the ICU raises a whole range of intersecting professional and ethical challenges for ICU staff, which broadly relate to decision-making, power, professional relationships and communication with relatives.

1.2.3.1. *Decision-making on behalf of patients*: ICU clinicians regularly make decisions regarding medical treatment on patients' behalf, because they are heavily sedated, or lack capacity to make decisions for themselves (Modra & Hilton, 2013). Examples include weighing up when to accept patients onto the ICU, provide resuscitation, withdraw or withhold treatment or allocate limited resources such as medical equipment and specialist staff (Nelson, 1997). These decisions often involve discussions between professionals that give consideration to the availability of resources, likely clinical outcome for the patient, the views of relatives and ethical and legal frameworks such as 'lasting power of attorney' (Modra & Hilton, 2013). Beauchamp and Childress (2009) have suggested an ethical framework that is commonly used to support ICU clinicians' decision-making, consisting of four key principles: 1) respecting patient autonomy in decision-making, 2) making decisions that are of benefit, 3) have more benefits than risks, and 4) avoid harm (Modra & Hilton, 2013).

1.2.3.2. *Communicating with relatives*: Communicating complex information to relatives, regarding a patient's diagnoses, treatment, prognosis and medical decisions can be a challenging task for ICU staff (Gauntlett & Laws, 2008). In a study conducted with relatives of ICU patients in France, over half reported feeling confused about the information they had been given by physicians, regarding their family member's care (Azoulay et al., 2000).

Clinicians regularly communicate medical decisions directly to relatives, such as the decision to deny or withdraw treatment. Such decisions tend to be made by senior ICU clinicians; however, at times, relatives may have differing opinions resulting in tensions with the staff team (Wahlin et al., 2010). These clinicians are

exposed to relatives' emotional reactions and must attempt to provide a containing presence, which can be psychologically and emotionally taxing (Modra & Hilton, 2013). ICU doctors reported this to be one of the most stress-inducing aspects of their work (Coomber et al., 2002). It can be particularly difficult for ICU staff to deliver bad news when treatments are not available due to systemic difficulties, such as resource constraints (Kalvemmark, Hoglund, Hansson, Westerholm & Arnetz, 2004).

*1.2.3.3. Professional status, power and decision-making:* Decisions about patient care can be divisive amongst ICU professionals. In a survey of 230 Australian ICU nurses, Bucknall and Thomas (1997) found that almost a third of respondents regularly disagreed with decisions made by other members of staff. Nurses tended to have similar views about medical decisions due to shared professional values, but often disagreed with those of physicians. A common source of disagreement relates to the cessation of active treatment and commencement of end-of-life care, and there is often considerable discussion before engaging in the latter (Papadimos, Maldonado, Tripathi, Kothari & Rosenberg, 2011). The source of such disparity may relate to the way in which professions view their roles, with nurses 'caring for' patients and physicians 'treating' patients. Therefore, when making decisions about patients that have a slim chance of survival, some physicians may favour intensive treatment in an attempt to preserve life, whilst nurses may prefer earlier withdrawal of treatment in order to limit suffering and provide a comfortable and dignified death (Bucknall & Thomas, 1997; Flannery, Ramjan & Peters, 2016; Gawande, 2015; Gutierrez, 2005; Wahlin et al., 2010).

Physicians often hold powerful positions within the ICU and have the responsibility of making decisions. As such, the views of other experienced ICU professionals may be subjugated (even if physicians are less experienced), leading to feelings of disempowerment (Bucknall & Thomas, 1997, Eisendrath & Dunkel, 1979). A lack of autonomy is a common complaint amongst nursing staff and is considered to contribute to higher rates of stress in comparison to their physician colleagues (Goodfellow et al., 1997).

1.2.3.4. *Ethical decisions and moral distress*: Moral distress was a term initially used by Jameton (1984) to describe situations in which resource, systemic and professional constraints prevent healthcare staff from providing treatment that they consider to be ethically and morally correct. These include many of the professional and ethical issues discussed above, including disagreements about treatment decisions between staff members and relatives, and difficulty communicating information about treatment and prognosis (Bruce, Miller & Zimmerman, 2013; Gutierrez, 2005). Moral distress can evoke anxiety, sadness, anger, frustration, disempowerment and internal and interpersonal conflict (Corley, 2002; Gutierrez, 2005). The American Association of Critical Care Nurses (2008) report that this can result in staff providing poorer care, that is less patient centered and lacks compassion. Distressed staff may avoid caring for particular patients and become discontented with their job (Wiegand & Funk, 2012).

Several studies have found that moral distress is notably higher amongst nurses than physicians, with professional power and decision-making ability thought to be a protective factor for the latter profession (Dodek et al., 2016; Whitehead, Herbertson, Hamric, Epstein & Fisher, 2015).

1.2.3.5. *Challenges in end-of-life care*: End-of-life care is initiated when clinicians decide that a patient has no reasonable chance of recovery. Between 15% and 24% of patients do not survive an ICU admission. As a consequence, doctors and nurses working on ICUs frequently provide care to patients who are dying, and practical and emotional support to their loved ones throughout the palliative stage (Donnelly & Psirides, 2015). Nurses play a key role in end-of-life care, whilst physicians may adopt a passive stance, due to the redundancy of their 'treating' role. This can lead to confusion around when and how treatment should be withdrawn and which professional group should take the lead with this process (Efstathiou & Walker, 2014).

Building a relationship with relatives is a crucial part of the nursing role and provides a foundation from which to communicate important information and convey compassion and empathy during challenging circumstances (Soderstrom,



Benzein & Saveman, 2003). However, when providing end-of-life care, nurses frequently report having difficulty locating professional boundaries. Close relationships with relatives can intensify emotional bonds, resulting in the experience of strong emotions when patients die. Some nurses feel uncertain how much emotion to share with relatives and how long they should provide them with support after a patient's death (Efsthathiou & Walker, 2014). Physicians that are involved in end-of-life discussions and care have reported experiencing emotional exhaustion when communicating with relatives and witnessing multiple deaths in a single shift (Donnelly & Psirides, 2015). Providing a patient and their relatives with good end-of-life care may be protective and experienced as rewarding, or at least less painful amongst some clinicians (Donnelly & Psirides, 2015; Shorter & Stayt, 2010).

#### 1.2.4. The Impact of Working in Intensive Care

The structural, clinical, ethical and professional challenges discussed above, including: high mortality rates, decision-making around withdrawal of treatment, supporting dying patients, staff conflict, high workload and poor organisation of teams, can place ICU staff under great stress and lead to burnout (Azoulay & Herridge, 2011). This may be compounded if staff feel as though they have little control within the context of a demanding environment (Bakker, Le Blanc & Schaufeli, 2005).

1.2.4.1. *Burnout syndrome*: 'Burnout syndrome' (BOS) is a term widely used in the ICU literature, to describe difficulties associated with the stressful and demanding nature of a working environment, including poor physical and mental health as well as reduced work performance (Azoulay & Herridge, 2011; Guntupalli, Wachtel, Mallampalli & Surani, 2014). BOS is reportedly widespread amongst ICU staff. Of 2392 French ICU nurses surveyed by Poncet et al. (2007), one third met the criteria for 'severe BOS' and were also more likely to experience low mood than other colleagues, whilst Embriaco et al. (2007) noted severe BOS amongst 46.5% of 978 French physicians surveyed. Burnout has also been reported in ICU staff working within a variety of countries, including Norway, Portugal, America and China (Guntupalli et al., 2014; Myhren, Ekeberg & Srokland, 2013; Teixeira, Ribeiro, Fonseca & Carvalho, 2013; Zhang et al.,

2014). Authors such as Bakker, Le Blanc and Shaufeli (2005) have suggested that BOS may be 'contagious' and 'spread' throughout teams.

1.2.4.2. *Compassion fatigue*: Being exposed to challenging aspects of direct patient care (e.g. intense pain and distress and repeated exposure to trauma) can lead to compassion fatigue. ICU staff experiencing compassion fatigue may present with: low mood, hopelessness, disempowerment, irritability, exhaustion, anxiety, avoidance and hypervigilance (Jenkins and Warren, 2012; van Mol et al., 2015). Compassion fatigue can impact a clinician's ability to care for and build relationships with their patients, reduce their capacity for containing emotions and empathising with the patient's situation. Staff experiencing compassion fatigue, have higher rates of sickness and absence from work and may be more prone to making clinical errors (Jenkins & Warren, 2012; The Royal College of Psychiatrists [RCPSYCH], 2015). Compassion fatigue therefore represents an acute reaction, whilst burnout develops over a prolonged period due to chronic environmental demands, but both can co-occur (Thompson, 2013). Compassion fatigue affects somewhere between 7% and 40% of ICU staff (van Mol, 2016).

1.2.4.3. *Mental health*: The stressful ICU environment has also been associated with an increased prevalence of mental health problems amongst staff. A survey of ICU physicians conducted by Coomber et al. (2002) in the UK found that 28.5% experienced distress that met the criteria for a diagnosable mental health problem, between 15-23% of staff experienced low mood, and higher rates of post-traumatic stress have been reported in ICU nurses compared with those from generic settings (Embriaco et al., 2012; Garrouste-Orgeas et al., 2015; Mealer, Shelton, Berg, Rothbaum & Moss, 2007).

#### 1.2.5. Protective Practices and Processes

Several aspects of ICU work have been described as positive and/or protective against the aforementioned demands. These include: applying specialist skills and knowledge to save lives and reduce suffering, witnessing improvements in patients' health, hearing stories of recovery post-discharge, building relationships with patients and relatives, an ability to successfully manage difficult conversations and being part of a supportive and communicative team that are

able to share expertise, pull together in a crisis and provide praise for examples of good practice (Wahlin et al., 2010). These factors can bring a sense of meaning and enjoyment to ICU work, which are protective against stress and burnout (Andolhe et al., 2015).

Dannenfeldt (1982) considers the expression of feelings between ICU staff, to be one of the most helpful means of managing emotional responses that arise within day-to-day clinical work. ICU teams implement various practices to encourage this, such as: discussion groups for staff grieving the loss of patients, peer-support and debriefing after critical incidents, group supervision and reflective spaces in which clinicians can discuss ethical dilemmas and emotional reactions to particular cases (Caine & Ter-Bagdasarian, 2003; Lenart, Bauer, Brighton, Johnson & Stringer, 1998; Lindahl & Norberg, 2002; Lown & Manning, 2010). Reflecting on experiences in these fora may help ICU staff to feel more empowered within challenging clinical scenarios and reduce the likelihood of experiencing moral distress and compassion fatigue (Wiegand & Funk, 2012).

### **1.3. The Challenges of Intensive Care work and Advanced Technology**

The discussion above has highlighted how ICU doctors and nurses are exposed to a variety of clinical, ethical and professional issues, which may impact their mental and emotional well-being. Key challenges such as the adaptation of clinical practice, decision-making, and communication with relatives are often associated with the use of advanced, lifesaving technologies in the ICU, which are administered to critically ill patients straddling a 'grey area' positioned somewhere between life and death.

ECMO is a hyper-advanced technology that operates on the boundaries of intensive care practice. It is utilised in advanced practices in heart and lung care when conventional therapies have been ineffective and can be used to support the process of heart and/or lung transplantation. It therefore offers extremely sick patients their very last chance of life (Starck, Hasenclever, Falk & Wilhelm, 2013). Given that the focus of ECMO is at the high-end of intensive care provision, it is likely that many of the clinical, professional and ethical issues that commonly

arise in intensive care practice might occur more frequently and/or become amplified when supporting patients with ECMO. The next part of this review is dedicated to exploring in more depth, what is currently known about the nature of the clinical, professional and ethical challenges specifically associated with ECMO, and the experiences of specialist staff working with this technology.

#### **1.4. An Introduction to ECMO**

ECMO is a form of life-saving technology that is able to take over heart and lung function for people who are critically ill and is commonly administered in the ICU setting. It can provide ventilation and gas exchange (oxygenation of blood and removal of carbon dioxide), warming and circulation of blood around the body. ECMO is not a treatment, but a form of cardiopulmonary (heart and lung) support, which can allow the body to recover from a reversible illness, or buy time for further treatment or organ transplantation (Gay, Ankey, Cochran & Highland, 2005; Moiser et al., 2015; Thiagarajan & Barrett, 2011). ECMO initially gained traction in paediatric medicine, but began to be used more frequently amongst adults during the H1N1 swine flu pandemic in recent years. Confidence in its efficacy increased following the encouraging outcomes of a randomised-control trial (RCT) conducted by Peek et al. (2009), in the UK (Gattinoni, Carlesso & Langer, 2011).

##### **1.4.1. 'Varieties' of ECMO**

During ECMO support, cannulas are placed into the body in different ways (e.g. through the neck [jugular] or large veins in the legs [femoral vein]) to form 'circuits' (Wang & Honey, 2012). Martinez and Vuylsteke (2012) describe two of the most common ECMO circuits. Veno-Arterial (VA-ECMO) supports oxygenation of blood and its circulation around the body, bypassing the heart. It is used when the heart's ventricles are severely damaged and cannot pump blood around the body efficiently. Veno-Venous (VV-ECMO) has the primary function of oxygenating and removing carbon dioxide from blood (gas exchange), and circulating it through the body via the heart (Gulack, Hirji & Hartwig, 2014).

#### 1.4.2. Broad Uses and Benefits of ECMO

VV-ECMO is used to support patients with severe respiratory damage or failure, or hypoxemia (low oxygen levels in blood e.g. due to H1N1-flu). It can facilitate lung rest and recovery and is preferred to mechanical ventilation, as it is more protective of the lungs (Brodie & Bacchetta, 2011; Cianchi et al., 2011; Gay et al., 2005; Turner & Cheifetz, 2013). VA-ECMO is commonly used when cardiac function is poor, during septic shock (drop in blood pressure as a result of infection), and amongst individuals who have ingested poisonous material or suffered severe trauma affecting multiple organs. It can also resuscitate patients following a cardiac arrest without the need for chest compressions, known as extracorporeal cardiopulmonary resuscitation (ECPR) (Moiser et al. 2015). In recent years, ECMO has been utilised to support people with end-stage heart or lung diseases, who are awaiting a transplant. This strategy is known as 'bridging' and aims to buy time so that a donor organ can be found. It also has utility for supporting patients experiencing complications post-transplant and before or after cardiac surgery (Chou et al., 2013; DePasquale et al., 2013; Gulack, Hirji & Hartwig, 2014; Stulak et al., 2009).

#### 1.4.3. Specialist Care Practices

Patients being supported with ECMO tend to have highly unstable and complex medical conditions which are difficult to manage. However, ECMO brings its own challenges and complications, due to the complex interaction between the patient and their condition, environmental factors (e.g. infections), aspects of care (e.g. drug administration) and complex machinery and circuitry (Abdelbary, 2017).

Regular nursing duties such as personal care and mobilisation of patients must be modified and performed carefully to avoid causing damage to the patient or ECMO circuit (Boling, Dennis, Tribble, Rajagopalan & Hoopes, 2016). Frequent checks must be performed to reduce risks of complication and/or deterioration, for example, ensuring that cannulas remain inserted correctly and that there are no signs of bleeding, infection or problems with the ECMO machine and circuit (Allen, Holena, McCunn, Kohl & Sarani, 2011; Bombino, Radaelli & Patroniti, 2014; Gay et al., 2005; Hijjeh, 2017).

Problems can occur during the cannulation (placement of cannula), weaning and decannulation (removal of cannula) processes. Incorrect placement of the cannula can result in heart attack, nerve damage, infection or bleeding (Miranda et al., 2012; Stulak et al., 2009). Anti-clotting drugs are given to prevent blood clot formation. Administration must be 'just right' to avoid risk of complications (Wang & Honey, 2012). Weaning from ECMO is indicated when organ function has improved (Allen et al., 2011; Bombino et al., 2014)

#### 1.4.4. ECMO Retrieval

ECMO is a technology that requires specific expertise and is often offered by specialist centres (Burrell, Pellegrino, Pilcher, Bernard & Kennedy, 2012). As such, patients with heart and/or lung problems who are not responsive to standard treatments and require ECMO, may be retrieved from other hospitals nationally and internationally. Specialist 'ECMO retrieval' teams travel to other hospitals, place patients on ECMO, and transport them back to a specialist centre for further care by trained staff (Eriksson, Frenckner & Broman, 2016). ECMO retrieval provides increased capacity to support critically ill patients from a broad geographical area, which has proven useful during flu pandemics (Jones, Hommers, Burns & Forrest, 2010).

#### 1.4.5. Evidence Base and Complications

Common complications associated with ECMO include brain or lung hemorrhage and stroke, renal (kidney) failure and liver damage, excessive bleeding, heightened risk of infection and pneumonia. Neurological problems and physical disability are also common long-term difficulties of former patients, impacting quality of life. The VV-ECMO circuit used to support severe lung problems is associated with fewer risks and complications (Lindstrom, Pellegrino & Butt, 2009; Makdisi & Wang, 2015).

A systematic review conducted by Tramm et al. (2015) highlights that only Four Randomised Controlled Trials (RCTs) have been conducted to evaluate the efficacy of ECMO in adults, in comparison to regular ICU care. All have focused specifically on patients with respiratory failure. No significant difference was observed in mortality rates amongst ECMO and non-ECMO treated patients. In

contrast, a meta-analysis conducted by Zangrillo et al. (2013) considering outcomes for VV and VA-ECMO patients, and indicated that around half of all patients who would have likely died without ECMO intervention, survived after receiving support.

Makdisi and Wang (2015) suggest that survival for VV-ECMO patients with severe respiratory failure can reach 60-70% when they are transferred to a specialist ECMO centre. Outcomes for patients being supported with VA-ECMO are much poorer (20-30% survival). Further technological and procedural advancements, such as administering ECMO when patients are conscious, can reduce the risk of complications (such as those associated with sedation), support swifter rehabilitation and are likely to continue to improve outcomes (Bastin & Firmin, 2015; Langer et al., 2016).

#### 1.4.6. Experiences of ECMO Care

ECMO is a complex technology that can preserve life where other treatments or technologies are unable to do so. ECMO care therefore throws up a number of more specific professional, ethical and clinical challenges in addition to those documented in more general ICU work, such as: whom ECMO should be offered to given that it is a limited resource, under what circumstances it should be withdrawn (therefore who lives and dies), the way in which technical and prognostic information is conveyed to patients and relatives and their role in decision-making. Due to the growing use of ECMO in intensive care and emergency medicine, several authors have attempted to explicate the experience of these issues from patients' and relatives' perspectives (Aylott, 2002; Chen et al., 2016; Curley & Meyer, 2003; Epps & Nowak, 2010; Harris-Fox, 2012; Tramm et al., 2016a; Tramm et al., 2016b).

### 1.5. Systematic Literature Search

A systematic literature search was conducted to find out more about staff experiences of working with ECMO through documented accounts, and to obtain a comprehensive understanding of key professional, ethical and clinical practice issues affecting staff working with this technology. The literature review was

guided by Booth, Sutton and Papaioannou's (2016) framework for a comprehensive and systematic literature search, as detailed below.

#### 1.5.1. Phase One: Selecting Search Criteria

The selection of search criteria involved: 1) identification of scientific databases in which to conduct the literature search, 2) identification of key search terms relating to ECMO and clinical experiences of ECMO.

1.5.1.1. *Database selection:* University of East London (UEL) library resources provided access to several databases relating to biomedical and social sciences. Discussion with subject librarian and supervisors, indicated that the following databases would provide a good coverage of relevant journals from biomedical and social sciences, and issues relating to ECMO and the roles of nurses and physicians: 1) Medline/PubMed, 2) CINAHL, 3) Academic Search Complete, 4) PsycARTICLES, 5) PsycINFO, 6) SCOPUS.

1.5.1.2 *Identification of key search terms:* Major search terms were identified from key words in the project title and synonyms of these terms, as recommended by Booth, Sutton and Papaioannou (2016). Other related terms that aligned closely to the selected major search terms were derived from broader issues impacting intensive care staff, identified within the narrative review above. Table i. summarises the terms used in the systematic literature search.



Table i.  <i>Relevant Major Search Terms, Synonyms and Other Related Terms Used as a Basis for Literature Searching</i>	
<u>Key term</u>	<u>Synonyms/Related Terms</u>
Extracorporeal Membrane Oxygenation	ECMO
Staff	Nurse Doctor Physician
Experiences	Psychological, stress, burnout, coping, psychological growth, resilience, ethics, ethical, malfunction, error, moral distress, compassion fatigue.

### 1.5.2. Phase Two: The Process of Conducting the Literature Search

1.5.2.1. *Searches derived from thesauri and major subject headings:* EBSCO databases provide a thesaurus function, which enables a more structured search by selecting articles with specific major subject headings attached. Searching in this way accounts for differing terminology that may be used to describe the same related concept and is therefore considered to be a more accurate means of identifying relevant articles (Booth, Sutton & Papaioannou, 2016). CINAHL was chosen as the key search engine for a thesaurus search, due to its medical focus

and because it was the only search engine available that incorporated “extracorporeal membrane oxygenation” as a major subject heading. Subheadings were used as a means of limiting the search to the most relevant articles. Selected subheadings closely resembled topics raised in the initial narrative review above. Appendix A includes a table describing major subject headings and subheadings used in thesaurus searches, along with the number of relevant papers identified.

*1.5.2.2. Searches derived from free-text and boolean phrases:* Free-text searches were used in databases where thesauri were unavailable. Boolean logic was utilised to enhance the search, using “AND” to combine concepts and provide a more specific search. To search for highly specific papers documenting staff experiences of ECMO, several terms were combined (e.g. "Extracorporeal Membrane Oxygenation" AND “Staff” AND “Experiences”). Less specific searches were used to locate papers addressing topics likely to relate to staff working with ECMO (e.g. “ECMO” AND “Ethics”). The table in appendix A details the boolean phrases used and the number of relevant articles found from each search.

*1.5.2.3. Included and excluded articles:* Articles in the initial search were deemed relevant following an appraisal of the article title and the content of the article abstract. Articles were excluded from the search if they focused on the use of ECMO in children, due to this the specific focus on adults for this research. A total of 59 relevant articles were found in the initial search. An additional six were identified from the reference lists of the papers found in the initial search, which were used to elaborate specific aspects of the literature review below (total=65). Thirteen articles were excluded for the following reasons: 1) Mismatch between article name/abstract (Two articles), 2) article focused on Pediatric ECMO despite there being no indication from the article title and abstract (Five articles), the full article did not engage with issues pertinent to the review (Six articles), leaving a total of 52.

## 1.6. Findings of Systematic Literature Search

The systematic literature search revealed that only three qualitative studies had previously considered staff experiences of working with ECMO. A mixed methods study by Honey and Wang (2012) included a qualitative component, focusing on specialist ECMO nurses' experiences of treating patients during a flu pandemic in New Zealand. A similar study was conducted by Corley, Hammond and Fraser (2010), documenting Australian specialist nurses and medical staff experiences of a flu pandemic. In addition, a specific qualitative study conducted by Harris (2002) focused on understanding ECMO nurses' experiences of working in a context where it was being withdrawn from patients at the end-of-life. It is therefore clear that few researchers have considered ICU staff accounts of working with ECMO, and their relationship to and experience of: the clinical, professional and ethical issues highlighted above, the practical challenges of the work and the psychological and emotional impact on staff.

The specific 'ECMO focused' literature review below considers the findings of all of the relevant articles identified by the literature search, including the specific articles relating to staff experiences, highlighted in the paragraph above. Given the large number of articles identified, the review addresses the key issues raised under a number of headings, which broadly consider the specific professional and ethical challenges associated with ECMO and the impact on staff working practices and well-being.

## 1.7. Challenges of Working with ECMO

### 1.7.1. Professional and Ethical Challenges of Working with ECMO

The majority of the papers (35) identified in the literature search related to the ethical issues around the use of ECMO, suggesting that this is an area of significant interest and concern to clinicians.

1.7.1.1. *Cost vs. benefit.* As has previously been discussed, the evidence base remains unclear in relation to the efficacy of ECMO. There are a number of barriers preventing clinicians from establishing its efficacy in relation to particular

patient groups (Allen et al., 2011). For example, it is not considered ethically appropriate to place patients waiting for a transplant in a 'control treatment group' vs. ECMO as part of a robust RCT, because this involves denying patients the best treatment, and may increase their chances of death (Abrams et al., 2014). This is similarly the case when attempting to consider the merits of conventional cardiopulmonary resuscitation (CPR) vs. ECPR (Chen & Chang, 2008). Berry (1989) argues that such scenarios are unacceptable and that RCTs are not required to establish the efficacy of ECMO. Instead, a number of authors suggest that analysis of historical patient outcomes adequately demonstrate that ECMO has benefit for particular groups and that patient outcomes are improving (Bluhm, 2010; Crow, Fischer & Schears, 2009; Truog, 1992). Nevertheless, ECMO RCTs continue to be conducted and authors such as Morris (1993) and Campbell (1994) argue that they can help to establish the circumstances under which ECMO is most effective.

ECMO is an expensive and resource intensive intervention. Disagreement about its efficacy for particular groups, makes it difficult to apply in a utilitarian manner (Abrams et al., 2014). Combes et al. (2014) argue that ECMO should be used within specialist tertiary ICU centres, by clinicians who have the expertise and experience to select appropriate patients and are au fait with initiation, management and withdrawal practices (Crow et al., 2009).

*1.7.1.2. Initiating ECMO:* The decision about initiating ECMO often lies in the hands of ICU doctors and is made on behalf of patients that lack capacity. Decision-making is uncertain, because of unpredictable outcomes (Crow et al., 2009). When deciding whether to place a patient on ECMO, consideration is given to: whether the patient's heart or lungs are likely to recover, their age (e.g. older patients may have poorer outcomes), whether they have already had mechanical ventilation and if they have other severe physical complications such as multi-organ failure or brain injury (Allen et al., 2011; Schmidt, Brechot & Combes, 2016). The challenge for clinicians is to make such decisions under significant time constraints (Bein, Webber -Carstens & Herridge, 2015; Ramanathan, Cove, Caleb, Teoh & McClaren (2015).

Clinicians may utilise scoring systems to support decision-making around initiation. For example, the Respiratory Extracorporeal Membrane Oxygenation Survival Prediction (RESP) score and the PRESERVE mortality risk score allows clinicians to predict patient survival and quality of life, using calculations that consider a range of factors such as: health status, treatment practices and age (Schmidt et al., 2013; Schmidt et al., 2014). However, these calculations are limited in scope and are not suitable for use in all contexts. For example, they cannot predict the range of complications that might arise. Therefore decisions to initiate ECMO are essentially judgements, supported by evidence, clinician knowledge and experience, and the views of patients and relatives (Crow et al., 2009, Fan & Pham, 2014; Senussi, 2014).

1.7.1.3. *End-of-life and withdrawal of ECMO*: In the UK relatives are often asked their opinion about medical decisions, but legally, final decisions usually reside in the hands of doctors. Relatives views relating to decisions about the withdrawal of ECMO, may conflict with ethical principles adopted by clinicians, such as making decisions that are of benefit to the patient, or that minimise harm (Beauchamp & Childress, 2009; Ramanathen et al., 2015). In addition, as the practice of 'awake ECMO' (supporting patients whilst conscious) becomes more widespread, patients are likely to have increasing participation in the decision-making process (Meltzer et al., 2014).

Jaouni (2017) describes a clinical case in which a patient was conscious whilst on ECMO and able to make decisions about their own care. The patient chose to continue receiving ECMO support, despite knowing that their condition was untreatable. Patient decisions in such situations can be unreliable, because of heightened emotion, distorted cognition and difficulty understanding the nature of and evidence surrounding the intervention (Peetz, Sadovnikoff & O'Connor, 2015). These problems may also impact the decisions of relatives, who may favour continuation of ECMO, even when doctors' recommend withdrawal, due to poor prognosis (Ramanathen et al., 2015). Ramanathen et al. (2015) suggest that when patients and relatives are involved in decision-making, clinicians should clarify the potential complications and limitations of ECMO, and clearly outline the circumstances under which it would be withdrawn (e.g. no chance of

recovery), prior to obtaining consent. However, some ECMO nurses have advocated for making decisions on behalf of relatives, because it can alleviate the potential burden of decision-making and the possibility of experiencing guilt for 'getting it wrong' (Harris, 2002). In addition, physicians may feel that their superior medical knowledge leaves them best placed to make decisions around the withdrawal of ECMO and as such, can be resistant to conceding decision-making power to patients and relatives (Meltzer et al., 2016). However, relatives have been known to contest these views.

Due to their frequent contact with the patient and relatives, ECMO nurses consider themselves more in touch with patient suffering at the end-of-life and therefore, may come to terms with the idea of withdrawal of treatment before doctors (Harris, 2002). This finding fits with those of other non-ECMO focused studies conducted in general intensive care settings (Flannery et al., 2016). ECMO nurses consider that decisions to withdraw ECMO should be multidisciplinary, with the responsibility of 'the final decision' remaining 'the doctors' domain' (Harris, 2002).

1.7.1.4. *ECPR, do not resuscitate (DNR) and ECMO*: Traditionally the DNR order is put in place by a patient to prevent staff from administering chest compressions, because of poor prognosis. Since VA-ECMO can provide continuous resuscitation without chest compressions, consideration must be given to what DNR means, and when it should be instigated (Ramanathan et al., 2015). Meltzer, Ivascu and Fins (2014) propose that in such circumstances, DNR should be defined as the withdrawal of VA-ECMO. Abrams et al. (2014) suggest keeping abreast of deterioration in a patient's condition when they have a poor prognosis, and to adjust care plans, so that they are not resuscitated when there is little hope of survival or quality of life. Doing so may prolong the patient's suffering and result in a 'bridge to nowhere' scenario (see 1.7.1.5.). Ramanathan et al. (2015) advocate for clear guidelines being negotiated with patients and families with regards to what DNR means in the case of ECMO, for example turning off the machine or removing cannulas.

1.7.1.5. *The 'bridge to nowhere'*: ECMO is often used as a bridge to transplantation or the implantation of a device that can support the functioning of the heart, such as a Ventricular Assist Device (VAD). However for some patients, ECMO may sustain life, but offer little long-term quality of life. For example, when a patient's condition cannot be treated or they are ineligible for transplant, patients can be kept alive, but must remain confined to the ICU with no prospect of further treatment (Abrams et al., 2014; Schmidt et al., 2016). There are incidences where patients have been supported for over 300 days in such situations (Raza, 2017). Bein et al. (2015) question whether such practices simply prevent patients from having a dignified death, which can become a moral dilemma for clinicians.

1.7.1.6. *ECMO and organ donation*: ECMO has also been used in some instances to support organ donation. After obtaining consent, clinicians administer ECMO in a specific way after death to prevent it resuscitating the patient. The premise of this is to protect organ integrity and improve the success rates of transplantation. However evidence for this practice is lacking and several ethical issues have been highlighted. For example, ECMO cannulas may be inserted before death and may cause pain, further physical complications and damage the person's body (Dalle Ave, Gardiner & Shaw, 2016; Dalle Ave, Shaw & Bernat, 2016). ECMO may also be administered after brain death to preserve organs, but there can be difficulty identifying when brain death has occurred (Muralidharan, Mateen, Shinohara, Schears & Wijdicks, 2011).

1.7.1.7. *Communicating with patients and families*: Chen et al. (2014) have demonstrated that overemphasis of the success of ECMO in the media; can set up unrealistic expectations amongst relatives. Hopes for a miracle outcome often have to be managed by clinicians. Some achieve this by being candid with relatives, about the patient's chances of survival and by placing a limit on the time that ECMO will be used. However, if relatives disagree with such decisions, conflict can emerge (Allen et al., 2011; Bein et al., 2015; Ramanathan et al., 2015). Whilst doctors might play a key role in communicating major decisions to relatives, nurses often have daily contact with them, and provide updates on the patient's progress, as well as emotional support, as and when it is required (Gay

et al., 2005). Specialist Palliative Care Nurses may support this process (Klinedinst, O'Connor & Farabelli 2017).

### 1.7.2. Impact on Staff Working Practices

In addition to the professional and ethical demands highlighted above, working with ECMO also has specific implications for staff working practices, beyond the demands of the general ICU.

1.7.2.1. *Staffing pressures during high ECMO demand:* It is generally recommended that a minimum of two nurses care for patients being supported by ECMO, in order to manage the complex interaction between patient and machine (Bombino et al., 2014). Therefore ECMO support is relatively resource intensive. Both Corley et al. (2010) and Honey and Wang (2012) found that during flu pandemics, ECMO teams could be asked to work extra shifts and forgo breaks in order to manage the additional workload, ease pressure on the ICU and to support colleagues, leading to them feeling overworked and fatigued. Understaffing was also noted as a major difficulty during the Australian flu pandemic, due to the high numbers of patients admitted, impacting ECMO staffs' ability to follow agreed protocols and led to junior staff having to 'skill up' and take on greater clinical responsibilities. This created a knock-on effect, with greater pressure being placed on more senior staff to provide support, leading to increased anxiety (Corley et al., 2010).

1.7.2.2. *Challenges of ECMO retrieval:* Patients being supported by ECMO represent some of the most complex inter-hospital transfers. Therefore transportation should be well planned and the risk and benefits thoroughly assessed (Ellinger & Wydro, 2009). A limited literature base has considered the challenges that can occur during ECMO transportation. Bryner et al. (2014) and Ericsson et al. (2017) have documented common difficulties, such as: problems with the ECMO circuit or damage sustained during movement of the patient, electrical and equipment failure, missing equipment, and complications with the patient's physical health due to the instability of their condition. Despite these complications, patient deaths rarely occurred. Broman, Holzgraefe, Palmer and Frenckner (2015) have demonstrated that complications can be effectively



managed, providing retrieval staff have adequate resources and training. ECMO retrieval can be an uncomfortable experience for staff, who have to provide care in cramped and noisy conditions (Bryner et al., 2014). They may also experience fatigue, relating to the long shifts associated with retrieving patients from hospitals located in distant destinations (Jones et al., 2010).

*1.7.2.3. Training, education and practice:* There is a tendency for ECMO to be used in specialist centres, with the resources and expertise to utilise it safely and appropriately (Hastings, Pellegrino, Prevolos & Salamonsen, 2008). The development of the specialist roles such as the 'specialist ECMO nurse' has allowed professionals to develop specific skills and competencies, in order that they can care for patients more autonomously. For example, specialist ECMO nurses are able to manage day-to-day patient care and upkeep of the ECMO machine in the absence of a perfusionist [specialist in managing patient care relating to heart-lung bypass machines, and ECMO], limiting the need for perfusion expertise to emergency situations (Monegro, Beck & Charette et al., 2013; Society of Clinical Perfusion Scientists of Great Britain and Ireland, 2008). Training courses have been established so that nurses can develop the skills and competencies necessary for this specialism (O'Brien & Pellegrino, 2008). Training offers an important means of ensuring that patients are given the best quality care and that clinical practice is safe. Education may take place in daily practice, by attending workshops and courses and through skills sharing and inter-professional meetings and via 'simulation training', which involves learning to manage emergencies with the patient and/or machine through practice scenarios (Brum et al., 2015, Corley et al., 2010, Hijeh, 2017).

ECMO training may create a professional divide between staff who have been trained and not trained, due to differences in skills and responsibilities. Some ECMO nurses have suggested that they should be paid more due to increased specialism, responsibility and risk involved in their role (Corley et al., 2010; Honey & Wang, 2012). Training programs have been criticised for not providing enough teaching around the ethical dilemmas associated with the work (Jaouni, 2017).

### 1.7.3. Impact on Staff Well-Being

The professional, ethical and practical challenges of working with ECMO have been noted to have a detrimental impact on the well-being of specialist ECMO staff. However, a number of facets of the work have been reported as protective and/or fulfilling, motivating staff to continue to work with critically ill patients requiring ECMO.

1.7.3.1. *Detrimental impact on well-being:* There is limited research into the impact of working with ECMO, on staff well-being. Honey and Wang (2012) found that 61% of ECMO nurses surveyed in New Zealand, experienced caring for extremely sick patients as having a 'great' or 'severe' impact on their well-being. ECMO staff have identified a range of stressful experiences in their clinical practice such as: working in isolation, being at risk of infection with flu and having to wear protective equipment such as gowns or masks. Some have also experienced low mood when working with patients that had similar personal attributes to themselves, and difficulty coping with the unpredictability of supporting patients with flu and managing the needs of their families (Corley et al., 2010).

Harris (2002) found that ECMO nurses could experience distress if they had to care for patients and support families through the end-of-life, but had not been involved in the decision-making process to withdraw ECMO or disagreed with decisions that had been made. In addition, several authors document experiences of moral distress amongst clinical staff who disagree with decisions around the withdrawal of ECMO, or have to care for patients where ECMO is being used as a 'bridge to nowhere' (Jaouni, 2017; Klinedinst et al., 2017; Raza, 2017; Williams & Dahnke, 2016).

1.7.3.2. *Mitigating interventions:* Several authors have advocated for regular formal and informal meeting spaces, in which health professionals can express their views and share emotions relating to end-of-life decisions and 'bridge to nowhere' scenarios. These may take the form of debriefing and reflective spaces, in which professionals can reflect on clinical cases and the decisions made to

inform their practice (Harris, 2002, Ramanathen et al., 2015; Raza, 2017). Honey and Wang (2012) also recommend that counseling services are offered to staff.

1.7.3.3. *Positive experiences*: ECMO trained staff have reported enjoying working in the context of a challenging ICU and ECMO environment, supporting patients with complex health needs. The experience of working in such demanding scenarios has been said to advance their clinical knowledge and skills. There is also evidence that ICU staff enjoy the experience of teams coming together and supportive inter-professional relationships that develop under challenging and high pressure circumstances (Corley et al., 2010, Honey & Wang, 2012)

#### 1.7.4. Rationale, Purpose and Aims of this Research

As indicated in the review above, there are a number of ethical and clinical practice issues relating to ECMO, such as: making decisions about who scarce ECMO resources should be allocated to, how long it should be used for, the circumstances under which it should be terminated and who has a say in such decisions. In addition, the practices associated with working with ECMO require more specialist training and alterations to traditional working practices and responsibilities. These issues very much set work with ECMO apart from routine clinical duties in the ICU, and thus there is a need to understand how they impact specialist ECMO staff.

Despite there being extensive discussions of ECMO in the academic literature, very little in-depth qualitative data has been collected in relation to the work of ECMO staff and their understanding of specific challenges of working with this technology. The majority of qualitative research in this area focuses on surface level practical experiences within specific contexts, such as pandemic flu or end-of-life decision-making and withdrawal. In addition, this literature has mainly focused on documenting nurses' experiences, and very little is known about those of doctors, despite them taking a key role in technical aspects of the work, as well leading ethical discussions and decision-making. The literature review above also indicates very limited reference to the positive aspects of working with ECMO, which mirrors a dearth of such accounts across published intensive care literature.

ECMO is being used more frequently with adults with various clinical presentations, within the context of the rapid progression of the technology. This research aims to obtain qualitative accounts of intensive care doctors and nurses work with ECMO, when supporting adults across a broad range of clinical contexts, to ascertain their perspectives on the positive and challenging aspects of the work. It will specifically seek to explicate the professional, psychological and social processes and broader impact on staff well-being.

### **1.8. Research Questions**

How do ICU doctors and nurses conceptualise the key ethical and clinical practice issues relating to their work with ECMO?

What is the psychological and professional impact on doctors and nurses managing these issues?

## **2. METHODOLOGY**

### **2.1. Epistemology**

This research was conducted from a critical realist position in line with Maxwell's (2012) stance, which suggests that ontologically there is a real world that exists, but that a person's experience of that world is inevitably influenced by a broad range of factors at differing levels, which they may or may not be aware of. This can be understood using Bhaskar's (1997) three levels of ontology: 1) The empirical, relates to human experiences and the direct observations of people, 2) The actual, represents events that occur, but are not always observed or fully understood, and 3) The real, includes hidden underlying structures and mechanisms that influence the empirical and actual levels. Walsh and Evans (2014) encourage the use of this model when researching healthcare issues from a critical realist stance, because it allows for clear distinctions to be made between what may be directly experienced by research participants, and factors that influence these experiences but may not be within their conscious awareness.

The verbal accounts of participants in this study were not assumed to completely reflect all three levels of reality. Instead they would likely reflect the 'accessible' aspects of the reality of caring for patients with ECMO. For example, accounts at the empirical level might include physiological measurements and scans, indicating that a patient has serious heart or lung damage that might require ECMO. Patient's vital signs indicate progress or deterioration, whilst staff might observe changes in equipment functioning, and address them accordingly. The actual level might include complications experienced by the patient during ECMO and the events or changes that result in those complications. The experience of care from the patient and/or relatives' perspective would also be included here.

The researcher attempted to access 'the real' through a process of interpretation, by considering the underlying structures and processes at individual, organisational, social, professional and political levels as well at the historical

context, that influenced participants' surface level accounts of their work with ECMO (Willig, 2012). Examples include the way in which these factors influence decisions made by clinicians or the way in which staff cope with the challenges of the work. In a similar vein to Frosch and Saville-Young (2008), the interpretations about structures and processes underpinning the surface-level findings of this research, were considered to be possible ways of understanding and framing the accounts given by participants. This therefore suggests that accounts were influenced by context, rather than representing 'the truth'.

One criticism that might be levelled at much of the research conducted with critical care staff to date, is that it is perhaps too focused on the negative discourses of working in critical care, including 'stress' and 'burnout', with little elaboration of the positive experiences of such work. When designing and conducting this study, the researcher attempted to remain open to such experiences, whilst attending to any contradictions and/or tensions in participants' accounts.

## **2.2. Design**

Although there is a significant tranche of research considering how staff experience work in the ICU, the lack of research into staff experiences of working with specific technologies such as ECMO, suggested that this study was best conducted as an exploratory piece of work. A qualitative design was adopted as a means of obtaining in-depth, detailed accounts of participants' experiences of ECMO, grounded in examples from their clinical practice, due to the absence of any substantial research work. Semi-structured interviews were used as the primary method of data collection, allowing the researcher to provide a loose framework for the interviews, and participants to provide rich accounts of experiences that they considered to be most pertinent (Whiting, 2008).

Thematic analysis was chosen as the method of data analysis, since it has utility for 'mapping the terrain' in areas that are under researched. It was therefore considered the best means of identifying the broad clinical, professional, ethical

issues and psychological responses experienced by staff working with ECMO. An inductive approach was utilised, in which key themes were derived from deep analysis of the data, involving a process of interpretation at the 'latent level'. Thematic analysis also offers epistemological flexibility, and therefore had the capacity to facilitate an analytical process that was congruent with the critical realist epistemological stance adopted in this study (Braun & Clarke, 2006).

### **2.3. Ethical Approval**

Studies being conducted on NHS staff require ethical approval from a sponsoring organisation, in this case the University of East London (UEL). Ethical approval was sought from the UEL School of Psychology research ethics committee on 21<sup>st</sup> April 2016. The submitted document outlined key aspects of the research project, including its purpose, design, procedure, recruitment, participant information, ethical considerations, steps to ensure researcher safety and a risk assessment of interview locations. Approval was subsequently granted on 10<sup>th</sup> May 2016 (appendix B).

#### **2.3.1. Research and Development Approval and Indemnity**

As of 2016, research involving NHS staff requires research and development approval from a centralised body (the Health Research Authority [HRA]). HRA approval was sought by providing a project proposal and relevant project documentation that included a full overview of the research procedure and ethical considerations of the study. These were submitted via the Integrated Research Application System (IRAS). Project information was sent to the HRA via the IRAS on 16<sup>th</sup> June 2016 and approval was granted on 25<sup>th</sup> August 2016 (appendix C). After approval was obtained, a certificate of indemnity and sponsorship was provided by the University of East London Research Ethics Committee (appendix D).

## 2.4. Participants

### 2.4.1. Recruitment Context and Details of the ECMO Service

Research participants were recruited from a specialist ECMO centre in the UK, who provide ECMO support to patients across a broad geographical region. The centre also provides an ECMO retrieval service, in which patients from other hospitals across the country are placed on ECMO at their local hospital, and subsequently transferred to the specialist centre for ongoing care. The ECMO team was located within two separate ICUs provided by two hospitals within the same trust. At the time of writing, the trust website stated/indicated that it employed 21 consultants in intensive care medicine working directly in the ECMO service. This study recruited staff from both hospitals, within the trust.

*2.4.1.1. Details of the service model:* The service operated a 'devolved model' of responsibility, in which ICU nurses were given more autonomy in the care of patients on ECMO than is commonly the case in ECMO services. As part of this approach nurses provided the bulk of bedside care to patients being supported by ECMO in the unit. Doctors tended to take a lead in the planning of the/a patient's care and provided expert support during emergency situations along with perfusionists. Both doctors and nurses had received training to support the retrieval of patients from other hospitals. Due to a significant change in the staffing structure six months prior to recruitment for this project, additional staff capacity was bought in from a neighbouring NHS trust to support the training of new doctors and to ensure that the service could continue to run smoothly.

*2.4.1.2. Positioning of the researcher in the organisational context:* I previously worked as a Trainee Clinical Psychologist in the psychosocial service within the trust that this research took place. Part of this involved working with clients on the ICU. In this capacity, I worked briefly with two of the staff that chose to participate in the research, having observed their clinical work and participated in meetings that they had attended. During my previous work on the department, I had been party to discussions in which details emerged of a departmental reorganisation



that had significant repercussions for staff working on the unit. The impact of this was discussed by some of the participants in their interviews.

#### 2.4.2. Sampling and Recruitment Strategy

Palinkas et al. (2015) argue that it is useful to obtain a homogeneous sample of participants if a researcher's aim is to obtain in-depth data about a discrete group of people with specific knowledge or experiences of a topic. To this end, the following inclusion and exclusion criteria were adopted.

2.4.2.1. *Inclusion/exclusion criteria:* Doctors and nurses were specifically recruited for the study because they were the largest professional groups working with ECMO and many had roles dedicated specifically to the care of patients being supported by ECMO. Recruiting from both professional groups also ensured that there was a sufficiently large pool of potential participants. As indicated in the introduction, the professional practice of these groups is very much intertwined, suggesting that they were likely to form a homogenous group with broadly similar clinical duties. Other professional groups that work with ECMO, including perfusionists and surgeons were excluded from the study, since ECMO formed a smaller proportion of their working practice compared to specialist trained ECMO doctors and nurses.

Inclusion criteria were set, to ensure that participants had enough experience of working with ECMO and could provide detailed clinical examples of their work. To be considered eligible for the study potential participants were required to meet the following inclusion criteria:

- To be a registered ICU nurse or doctor, of any grade.
- To have received specialist practical training required to care for patients being supported by ECMO.
- To have participated in ECMO related work streams for at least six months, involving direct patient care, supporting relatives and supervision and management of staff working with ECMO, including work in other hospitals.

- To be engaged in ECMO work streams at the time of interview.

#### 2.4.3. Recruitment Process: Snowball Sampling

ICU staff may be considered a challenging group to engage in research due to the pressures of working in this setting including staff shortages, difficulty leaving a patient's bedside when providing care and needing to arrange cover to do so, and being required to rapidly respond to emergencies. Snowball sampling has been described by Atkinson and Flint (2001), as a useful means of recruiting interview participants from populations who are difficult to engage in research, because individuals with a specific interest or expertise in an area are more likely to participate. A snowballing approach was therefore adopted to recruit doctors and nurses from the ICU in which this study was conducted.

Patton (1990) recommends 'asking around' in the initial stages of snowball sampling, to locate individuals with significant knowledge of the research topic. As such, the recruitment process began with the researcher and field supervisor meeting with a lead clinician from each of the doctor and nurse staff groups, who identified 35 members of staff from the ICU who had significant experience in working with ECMO. These included 20 nurses trained specifically in ECMO retrieval and a further 15 members of staff, including 13 doctors, one nurse and one surgeon.

Each was contacted individually via the internal email system, with a standard message providing basic information about the research and how to find out more about participation (appendix E). Seven participants were recruited using this approach. These participants were then asked if they knew of other members of staff with ECMO experience who might be interested in taking part, which led to the recruitment of a further three participants. Professional leads supported ECMO trained staff to participate by encouraging them to participate on ECMO retrieval days, where they did not have dedicated patients to care for. In order to maintain confidentiality, members of staff referring potential participants were not informed of who took part.

2.4.3.1. *Establishing conceptual depth*: Nelson (2016) describes conceptual depth as a set of criteria that can be used during recruitment for qualitative research, to establish whether enough data has been gathered to understand a topic in sufficient detail, from a broad range of perspectives. It is considered preferable to the concept of theoretical saturation, which is said to be ambiguous and difficult to evidence. Recruitment for this study was ceased, when five conceptual depth criteria had been adequately met. Further description of this process is provided in appendix F.

## **2.5. Data Collection Procedure**

### **2.5.1. Obtaining Consent and Demographic Data**

Prior to commencement of the interview, participants were given an information sheet (appendix G), outlining the purpose of the research project, benefits and drawbacks of participation and their right to withdraw from the research at any time prior to commencement of data analysis. They were also informed of ways in which their confidentiality and anonymity would be assured, steps taken to securely store their data, and how to raise concerns about the way in which the research was conducted. After reading the information sheet, participants were asked if they had any questions about the project or the information provided. They were then given a consent form (Appendix H), which they signed if they agreed to the terms of participation.

2.5.1.1. *Confidentiality, anonymity and dissemination*: As part of the consent procedure, participants were informed that the interview data would be transcribed and that their name and any other personal identifiers (e.g. job title) would be excluded from transcripts, all written versions of the thesis, associated summary reports and any subsequent publications. They were told that the researcher planned to write a brief summary report of the research findings, which would be fed back to participants and members of the ECMO team to support professional learning, and that a paper would likely be prepared for publication in an academic journal.

2.5.1.2. *Collection of demographic data:* After consenting to participation, interviewees completed a form requesting key demographic information (appendix I), including: gender, ethnicity, age, professional status, years of experience of working with ECMO and whether they had attended specific ECMO training courses (see 2.5.6. for an overview of participant demography).

### 2.5.2. Other Interview Preparations

2.5.2.1. *Development of interview Schedule:* The interview schedule (appendix J) was developed using information gathered from the literature review, and was designed to generate data that would answer the research questions. It was reviewed by the director of studies (DoS) and the field supervisor (a Consultant Clinical Psychologist working in Intensive Care) prior to use. The schedule consisted of 15 questions that broadly asked participants about their job role in relation to ECMO, their general views about ECMO, its impact on their work and the challenges and positive aspects of working with ECMO.

2.5.2.2. *Overview of key research resources:* Interviews were recorded using an iGearPro digital voice recorder. An Apple I-MAC computer was used to store the interview data. iFunia Corporation's Multi-format video and audio player supported the playback of .WAV interview files. Microsoft Word 2011 was utilised for the purpose of data transcription and analysis. Handwritten notes made for the reflective log and during initial data analysis, were kept in a paper notebook.

2.5.2.3. *Research supervision:* Regular supervision was provided by both a director of studies from UEL and a field supervisor. The field supervisor provided practical support with accessing participants and acted as a gatekeeper for building relationships with senior ICU staff. The DoS supervised the broad management of the project and provided feedback on written drafts. Minutes of meetings were submitted and stored electronically via 'PhD Manager'.

2.5.2.4. *Interview locations:* Interviews were conducted in several private spaces in and around the ICU, to ensure participant confidentiality and anonymity. These included a surgical meeting room, a simulation training suite and participant's offices. The interview location was arranged in advance of the interview, on the

basis of availability and convenience for the participant. The field supervisor was informed via text message when the researcher was on-site conducting interviews, and of their safe completion. They agreed to contact the researcher if they did not receive confirmation of the latter.

### 2.5.3. Secure Storage of Data

Interview data was initially stored on the digital voice recorder, which was password protected with a four-digit pin code. Data was transferred to a password protected Apple I-MAC computer after interviews, and stored in an individually password protected folder and deleted from the voice recorder. Participants were informed that interview data would be securely stored for up to three years. Hard copies of paperwork with identifiable data (e.g. consent forms) were stored in a locked cabinet.

### 2.5.4. Structure and Process of Interviewing

In line with Whiting's (2008) guidance for conducting semi-structured interviews, opening conversations with interviewees focused on rapport building and making the participant feel comfortable. The initial questions therefore focused on their job role and specific duties and responsibilities in relation to ECMO. As the interview progressed, participants were asked broadly about challenging aspects of working with ECMO, as well as their positive experiences. Where necessary, prompts were used to stimulate further discussion. The researcher prefaced these questions, by asking participants to talk about examples from their own experience or clinical practice. The final broad topic of the interview focused on ways of coping with the challenging experiences, availability of support at an organisational level and suggestions for improvements in organisational support.

Whyte (1984) recommends that qualitative researchers maintain a fairly neutral stance when conducting interviews, by asking open questions to elicit responses from participants, and checking for correct understanding by summarising and reflecting back. This approach was adopted as a means of enabling the participant to have more control over the direction of the interview, rather than being led too much by the researcher. In addition, the interview schedule was not applied rigidly to each participant. Whilst all questions were covered in each

interview, they were not necessarily asked in the same order each time, allowing interviews to be led by participants' responses. If responses were too tangential (i.e. the topic of conversation moved away from ECMO for an extended period), the researcher referred back to the interview schedule to keep the interviewee on track. Use of the interview schedule also ensured that each participant talked about broadly similar areas in relation to their experiences of ECMO.

#### 2.5.5. Interview Debrief

To conclude, participants were asked about their experience of the interview and whether they had found any specific aspects to be challenging or distressing. Additional time was provided to individuals who wished to talk in more detail about their experiences. All participants were subsequently given a debrief form (appendix K), with details of services to support staff who may have experienced distress as a result of the interview, or in relation to their daily work. These included details of regular reflective practice sessions on the ICU, the staff counseling support service and how to access NHS mental health services through their general practitioner.

#### 2.5.6. Participant Demography

A total of 10 participants took part in the study, aged between 36 and 61 years. Four were male and six were female and had a variety of ethnic backgrounds. Of the participants recruited, five were trained ICU doctors (consultants) and five were registered ICU nurses. All participants indicated that they had received on the job training enabling them to work with ECMO and had attended specific study days or courses to support the development of their skills. Eight of 10 participants had been trained in ECMO retrieval. The most experienced participant had worked clinically with ECMO for 30 years, whilst the least had Two years of clinical experience.

Table ii.	
<i>A Breakdown of Participants' Ethnicity and Professional Grade/Job Role</i>	
<u>Ethnic Background</u>	<u>Number of Participants</u>
White British	4
Any Other Asian Background – Filipino	4
White Any Other European Background	1
Mixed European and Asian Background	1
<u>Job Title</u>	<u>Number of Participants</u>
Consultant in Intensive Care	5
Charge Nurse	1
Senior Staff Nurse	3
Staff Nurse	1

## 2.6. Data Analysis

### 2.6.1. Transcription

Bailey (2008, p. 127) describes transcription as a process of “reduction, interpretation and representation to make the written text readable and

meaningful". To achieve this, authors such as Banister et al. (2011) advocate simple verbatim transcription for most qualitative research. Bailey (2008, p. 129) suggests that researchers should attempt to obtain a balance between "readability and accuracy" when considering what level of detail to include in transcription. Since thematic analysis primarily focuses on the content of speech rather than the process of interaction, this study's interviews were transcribed at the semantic level (Sandelowski, 1994). To make the transcripts and excerpts used in the analysis more readable, standard written English was used, as opposed to regional or cultural variations in speech (Bailey, 2008). 'Filler' utterances such as 'um's' and 'ah's' were excluded from the transcription, as they were not considered pertinent to analysis and interpretation and punctuation was also added (Stuckey, 2014).

Some of the suggested transcription conventions provided by Bailey (2008), were adopted in order to make the interview data more meaningful. For example, conventions were used to mark overlapping or unclear speech, non-verbal communications and additional comments, which the researcher may have inserted at the end of utterances to give context to the data. Transcription conventions included: Inaudible (?), overlapping speech [Text], key non-verbal communications (Text), and {Text} researcher comments.

Interviewee's personal details were removed from the text in line with recommendations from Stuckey (2014), including place of work, name and level of job role. Participants were referred to by profession in interview transcripts, without reference to their level of qualification, for example nurse 1 (N1) or doctor 1 (D1). As a consequence, quotes could not be traced back to individual participants.

### 2.6.2. Data Analysis Procedure

Braun and Clarke (2006) suggest that when conducting research in an area that is under-researched, it can be useful for the analysis to take a broad focus, generating themes from the entire data set of transcribed interviews (data corpus). This approach was adopted alongside an inductive, bottom up method of coding, in which themes were derived directly from the data, rather than trying to



fit data into an existing theoretical framework. In line with the critical realist epistemological stance adopted by the researcher, data was analysed at the latent level, therefore exploring participants surface level accounts as well as interpreting them to uncover deeper levels of meaning, or hidden structures and processes underlying the surface level data.

The data analysis procedure broadly followed the analytic framework described by Braun and Clarke (2006). Following transcription, the researcher initially read through the entire data corpus for the purpose of familiarisation. Notes regarding broad patterns in the data were kept in a notebook. Transcripts were then printed and coding was conducted by hand. Individual segments of text were highlighted and corresponding codes written next to them (see appendix L for example). Transcripts were then re-read a week later in order to check the accuracy of coding. Similar to the process of analysis described by Wellman, Szlachcic and Lepori (2016), coded data was cut and pasted from the original transcripts into a computerised table on Microsoft Word 2011 and grouped by codes (see appendix M for an example). Grouping codes in this way enabled the researcher to split, splice and link codes as described by Joffe and Yardley (2004). For example, when compared, segments of text allocated to one code might be split into two more distinct codes, whilst similarities between two or more codes allowed them to be drawn together into a single code. In some cases, data fitted into several codes, but were eventually allocated to the 'code of best fit'. The researcher then considered how groups of codes merged together into subthemes and how subthemes grouped into superordinate themes, using the table to group and sort data. These initial themes and subthemes were then reviewed and refined, to ensure internal homogeneity (that data within themes clearly linked together) and external heterogeneity (that each theme had its own distinctive features) (Braun & Clarke, 2006; Patton, 1990). This involved re-reading the original data set and considering how well themes represented the data corpus, leading to further linking, splitting and splicing of subthemes and superordinate themes, in order to form final subthemes and superordinate themes (Braun & Clarke, 2006; Joffe & Yardley, 2004). The names of themes and subthemes were also refined in this process, which is illustrated in the thematic maps provided in appendix N.

## **2.7. Establishing Credibility of Data Collection and Analysis**

Norris (1997) argues that bias and error in qualitative research are inevitable and that rather than attempting to eliminate them, researchers should instead focus on increasing the quality and credibility of their research. Noble and Smith (2015) consider there to be four broad areas in which credibility can be assessed in qualitative research, including: Truth-value, consistency, neutrality and applicability. Below, consideration is given to the way in which the methods of collecting and analysing data addressed truth-value and consistency, whilst applicability and neutrality are examined in the discussion section of this report, in the context of the research findings.

### **2.7.1. Consistency of Data Collection and Analysis**

Noble and Smith (2015) state that to achieve consistency, qualitative research should clearly state the methodologies adopted in adequate detail and demonstrate how decisions about the methodology were made as the research progressed. The descriptions below outline how consistency was achieved in this research project.

*2.7.1.1. Consistency in data collection:* The researcher stuck as closely as possible to the data collection, transcription and analysis methodologies described above. Throughout the process of data collection, the researcher kept a reflective log as a means of considering challenges that arose, and the thoughts, feelings and behaviours that they evoked. Gibbs (1988) reflective cycle was used as a framework to guide thinking about what could be learned from specific challenges and how they could be handled differently. These reflections were discussed in meetings with the DoS, in order to ensure that a rigorous methodology was maintained. For example, the researcher considered the merits and drawbacks of changing the phrasing of a question on the interview schedule after an error was pointed out by a number of participants. Consideration of specific data collection dilemmas and associated decisions, are examined further in the discussion section of this report.

2.7.1.2. *Consistency in data analysis*: Alhojailan (2012) argues that when conducting a thematic analysis, qualitative researchers should seek the support of colleagues to triangulate analyses of interview data. It is most crucial to do this at the early stages of coding and theme development, because a differing perspective can help to identify bias in the analysis process, and ultimately leads to greater consistency and truth-value. As such, the initial codes derived from coding of the first two interview transcripts were shared and discussed with the DoS, prior to any subsequent coding. During the analysis, the process of reading and re-reading coded transcripts (as described in the data analysis procedure [see 2.6.2]) functioned as a form of 'test-retest reliability', in which the accuracy of coding was checked on a second occasion (Joffe & Yardley, 2004). Alhojailan (2012) also considers there to be utility in verification of the identified themes and subthemes after the analysis stage has been completed. The DoS therefore checked the identified themes and associated interpretations against data in the coding frame, to ensure that they were sufficiently consistent.

2.7.1.3. *Truth-value of findings*: In order to establish the truth-value of qualitative research findings, it is useful for researchers to reflect on ways in which their own frame of reference influenced data collection, analysis and interpretation (Noble & Smith, 2015; Norris, 1997). Interpretations of interview data were discussed with the DoS, to ensure that they were adequate and representative. Throughout the research process, the researcher detailed reflections within the reflective log, which considered how aspects of difference, including age, gender and professional status, might have impacted on the research process, in line with Smith's (2016) Social LA GRRRAACCEESS model. Consideration was also given to how the researcher's prior relationship to the research context (see 2.4.1.2.), may have influenced data collection and analysis. These and other useful reflections are outlined thoroughly in the discussion section.

### 3. RESULTS

As a result of data analysis of the interview transcripts, three superordinate themes were identified, with a total of seven associated subthemes. This section will provide a rich description of the analysis, utilising quotations from participants as supporting evidence.

Table iii.

*A Breakdown of Superordinate Themes and their Component Subthemes*

<u>Superordinate Theme</u>	<u>Subtheme</u>
Embodying the ECMO Specialist	The Paradox of Feeling Masterful and Inept
	Learning and Development
	Professional Drive, Personal Sacrifice
Team Dynamics	Team Spirit
	The Divisive Nature of ECMO
Riding the Emotional Rollercoaster	Extremes of Life, Death and Emotion
	Managing Emotions

### 3.1. Embodying the ECMO Specialist

Across the interviews participants talked broadly about how they and others viewed their role as a nurse or consultant working with ECMO as a specialist area of medicine.

#### 3.1.1. The Paradox of Feeling Masterful and Inept

In their role as ECMO specialists, nurses had significantly more autonomy and responsibility in caring for patients and the ECMO machinery. They felt skilled enough to manage the day-to-day care and monitoring of the patient and machine, and were able to spot complications emerging. This was liberating for nurses in the sense that they could operate with fewer constraints, such as seeking doctors' approval for decisions that were within their competence.<sup>1</sup>

N2: We have quite a lot of leeway in adjusting settings and it gives quite a lot of autonomy on the unit, with managing the ECMO patients, which I think has impacted on our practice and is maybe something that you wouldn't see in intensive care units everywhere.

I: What's it like, having autonomy with your kind of work?

N2: I think it's good, you feel like you have control and, if you feel that you have the skills and knowledge to make small changes, the doctors are mostly going to agree with your decisions and everyone is on the same page. (P. 7, Lines 102-112)

However, clinicians across the ECMO service had difficulty defining the limits of nurse competence and the boundaries of their role. Nurse participants in general felt competent to manage complications and technical emergencies, however some described taking on too much responsibility in this respect, and feeling out of their depth. There was an underlying anxiety amongst the broader ECMO team that this might lead to a catastrophic mistake and potentially a patient death, even

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<sup>1</sup> Participants can be identified from interview excerpts as follows: D1-5 = Doctors, N1-5 = Nurses, and I = Interviewer/Researcher.

though nurses often had no choice but to intervene before other professionals arrived.

N5: At some point we just managed to make it [ECMO machine] work again, but the feedback afterwards was that we shouldn't have done it. If you think about it, sometimes it's like "woah", because it was not the doctors who got involved. It was only the nurses. We were told that we shouldn't have reacted that way during that event. (P. 5, Lines 174-180)

Doctors described a sense of expertise and mastery, through their specialist skills and clinical accomplishments. They talked of working with colleagues from more general hospital settings and feeling as though they were able to offer more advanced diagnostics and clinical interventions than their counterparts. This was ultimately evidenced by their ability to save the lives of patients who would have otherwise died. This sense of expertise also gave them confidence in providing expert advice on the clinical management of patients to generalised physician colleagues.

D2: You arrive there [at another hospital], you don't know the patient, you assess the patient and you need to decide what's the best for them. You need to make them better. They are very very sick, they are almost dying and you help them quite a lot. It's also the challenges of the work, to find out what's wrong with the patient and treat them appropriately and see the response. Most of the time it is a good response and this is rewarding. (P. 2, Lines 60-66)

D5: I think because I am involved in it actively as well and not every cardiac centre in the UK is, I'm quite well placed to make decisions regarding patients and what therapies are available for them potentially. Also, that goes in terms of advising colleagues. (P. 4, Lines 136-139)

The feeling of expertise and mastery was often present when dealing directly with the physical ECMO machinery and performing procedures, such as inserting the ECMO cannulae when attaching the patient to the machine.

D1: We all get a kick out of successfully doing something technically challenging, putting lines in small vessels and tubes and stuff. We learn to do it, there's all these safety issues if you don't do it well, so there's a sense of pride and achievement to have put in a new central line, or a new dialysis catheter, or a new ECMO catheter, do a T of E {trans-oesophageal ECHO} get some diagnostic information. It sounds banal, but you get a kick out of needing to do it and doing it well. (P. 2, Lines 71-78)

However, experienced consultants considered this feeling of expertise and technical mastery to be a 'red herring', in the sense that the really challenging aspects of the role involved complex decision-making and its interplay with the management of distressed relatives.

D1: Increasingly the senior consultant role is to delegate that interesting thing that you get a kick out of and pick up the pieces with the distressed relatives.

I: I guess it's quite tangible isn't it, doing a task well, putting a line in or something. Whereas I can imagine that it's not as easy to know if you've done well with.

D1: It's very difficult. (P. 3, Lines 80-86).

Decision-making was very much an area of challenge and uncertainty for doctors. Participants talked of 'loose guidelines' relating to the allocation of ECMO. Decision-making criteria appeared to vary across institutions and cultures. Decisions would often need to be made quickly, at times without discussion or reflection and may conflict with personal values, leading some participants to question them.

D3: The only really strong study suggests that patients over 65 shouldn't be offered ECMO. She was 73 almost 74, but she was in good shape.

I: Yeah.

D3: And we said no, only on the basis of the age of the patient and we have got no doubt that she would have a limited capacity to recover. I went

to an ECMO course abroad and they have a very different way of accepting and not accepting their patients. Age for them is not a strong argument for accepting or not accepting a patient. I thought about this patient and I wondered “did we take the right decision”? (P. 6, Lines 187-197).

Making decisions to continue or withdraw treatment were also hugely challenging. In this sense, doctors felt unsure of how to define a good outcome for the patient. Medically, this involved simply saving a life, but at an ethical and human level, the potential long-term quality of life of the patient needed to be considered. Patients were often unconscious or incapacitated, could not express their views and doctors had to second-guess the patient’s wishes, with relatives’ guidance.

D4: I think, we could all be happy, or happier, that we are making the right decision on behalf of the patient. A lot of the time it is guess work. It is people saying “oh, well I wouldn’t like that” and you have to say to them “well it’s not about you actually, it’s about the patient”. (P. 16, Lines 619-623).

One of the greatest challenges reported by doctors was communicating with relatives, including: imparting information about the extent of critical illness, how ECMO would be used to help the patient and breaking bad news, within the context of an emotionally charged environment. Doctors frequently felt unsure about how this information was received, and whether they had handled discussions adequately and appropriately.

I: What is it particularly about those things that make it hard to talk to the family.

D2: Sometimes it’s difficult emotionally, so you need to explain what’s going on and it’s not something that you like to tell the family. Sometimes people become upset by what you are saying. You need to approach them in different ways at different times, you know, be more gentle. It is



challenging, it's the sort of conversation where you cannot go there and bluntly say.

I: So there is a bit of a process to it.

D2: Yeah. (P. 5, Lines 173-182)

D1: Good news, bad news. Uncertainty, certainty. Do they actually understand what is going on? Because some of the concepts are difficult. Some of the things that are going on with a heart, lungs, kidney, brain. We try to use lay terms to explain complex medical interactions. The minute you get away from harsh, real, medical, precise, into lay, the opportunities for ambiguity and misunderstanding increase exponentially don't they. (P. 16, Lines 584-590)

### 3.1.2. Learning and Development

On-going learning was an important part of the ECMO specialists' role. On the technical side, this involved an in-depth theoretical understanding of ECMO and its interface with the patient, acquired through structured training. Upkeep of clinical practice was also important, in order to maintain confidence in practical abilities.

N1: First of all you have to be trained. You have to have the knowledge, the understanding of how this machine works and the physiology around it, you have to understand that.

I: Yeah

N1: Then you have the skills, the skills to become competent in using this machine. How to take care of the tubing and everything else. And then, also the emergency, you have to be trained, you have to be skilful in dealing with those things as well. (P. 7, Lines 236-244)

N3: I do look after ECMO patients whenever I get the chance. I do one-to-one nursing for twelve-hour shifts sometimes. It's just so that I don't forget, because sometimes you do. After a few months especially, after three, four months. (P. 4, Lines 149-153).

Learning often took place on the job through exposure to new clinical situations. Nurses were often thrown in at the deep end in new and challenging clinical scenarios, such as on ECMO retrieval. Participants talked of the high level of expectation they and colleagues placed on themselves, with regard to being proficient in such circumstances, even when lacking experience

N1: When we were just starting this retrieval service, one of my colleagues went out, that was very early, during the time that we were just brought to the scene. Nurse says “you have to come to the retrieval”. But the trolley that we used, there’s a ventilator on it, but apparently no one knows how to turn on the ventilator.

I: Right.

N1: So how would I feel if I was the nurse and I don’t know how to turn it on? I would be very, very quiet and I would be humiliated. (P. 20, Lines 717-724)

Doctors had no formal training for some of the more human aspects of their roles, such as communicating technical information and breaking bad news to relatives. Whilst there were opportunities to learn on the job, there was a sense that this did not necessarily provide an adequate grounding for such complex tasks.

D1: I’m approaching the end of my career and I’ve done an awful lot of this, as a consultant for thirty years and there really wasn’t anything other than example for me to learn from, and of course not all of the examples were good. (P. 5, Lines 156-159)

The process of individual and team reflection was also important. Colleagues discussed the outcome of clinical cases and learnt from them, in an attempt to feel more secure about unpredictable aspects of the work such as decision-making and the management of relatives. Reflection was an important process in the absence of any formal training in such areas.

D2: So we discuss the ECMO cases. The junior doctor presents the case and we all discuss if there was anything that didn't go the right way or if we would have done things differently and those sorts of things. (P. 7, Lines 224-227)

### 3.1.3. Professional Drive and Personal Sacrifice

Doctors and nurses both talked of a sense of pride that they were working at the forefront of medicine and were in a sense, innovators of clinical practice in this area, for their respective professions.

D1: We get to dabble with the forefront technology of medical care. Because there is a part of that in humans isn't there.

I: Yeah.

D1: They want to walk on the moon, and why? Well, because it's there, and we want to dabble with new ground breaking technology, but in this case it's not using a shiny machine that makes funny noises and is really cool to play with. It's actually a massive impact on potential for survival. (P. 10, Lines 369-377)

Doctors in particular had recognised how far clinical practices relating to ECMO had come, and the positive impact on patients' lives. These participants implied an insatiable drive to develop this area of medicine, which was associated with a culture of hard work and long-hours. Many talked of the immense personal sacrifices that they had made for this cause, including the impact on their health and family life.

D1: You can't just wallow in the glory of taking something literally, almost 100 percent risk of death, and now 70 percent get better and go home. We can't wallow and self-congratulate how well we've done. (P. 8, Lines 289-292)

D3; You can use yourself without thinking about anything else. But it's exciting and satisfying and that's why we are continuing with it I think. (P. 14, Lines 507-509)

D3: On a family point of view it's quite difficult, because I am here a lot of weekends and I have a son who is a year and a half old. So I'm missing big things. (P. 13, Lines 461-463)

### **3.2. Team Dynamics**

ECMO had a significant impact on the dynamics of the broader ICU team. On one hand doctors and nurses united to face the clinical and ethical challenges associated with ECMO and on the other, ECMO had been instrumental in the fragmentation of the entire ICU service.

#### **3.2.1. Team Spirit**

All of the participants interviewed made reference to clinical and ethical challenges across their respective domains of clinical responsibility. Doctors and nurses were in resounding agreement that these were best tackled as a team, and they provided a wide range of examples of inter and intra-disciplinary collaboration.

On the front line, nurses worked together in pairs in order to care for patients and the complex ECMO machinery. Nurses appreciated the support of their partner at the bed space, in the sense that it enabled them to provide high quality, safe personal care for patients, and to feel as though they were giving them some quality of life. They needed the support of several colleagues to provide such care. A strong sense of team spirit meant that nurses knew they could rely on colleagues to work flexibly and pull together, in order support each other and the patient when it was required.

I: When you are working with people on ECMO, is it different from any other intensive care work?

N1: It's different. How is it different? First of all you get two people. Sometimes it's nice to work with two people.

I: Yeah.

N1: So you share the work, you share the jobs amongst yourselves. It's quite good really. Especially if the patient is stable and there are two of you there, I personally can do a lot of things to my patient. Give them a good wash, shave them, wash their hair, brush their teeth, and tidy up their bed space. You have time for that. (P. 15, Lines 518-528)

N1: Also you have to coordinate with your other colleagues, because rolling them will require extra people. So maybe four people, to roll. So there's lots of planning of people when you're looking after an ECMO patient. (P. 16, Lines 562-565)

This sense of team spirit stretched beyond daily personal care, and played an important role in a variety of contexts, such as managing emergency situations or staff shortages on the unit. Most nurses were willing to work flexibly during busy periods recognising that they could only manage as a unit, but some were unwilling to compromise patient care by spreading themselves too thinly.

N3: There were some staff there who said "oh I'm not happy to help and I'm not happy to leave my patients". Well they are right. You can't leave your patient if it effects your pin number one day.

I: Yeah. (P. 10, Lines 372-374).

During emergencies, nurses had to trust in the abilities of their colleagues, and knew that they could rely on each other to 'step up' in order to manage problems relating to the ECMO machinery and/or deterioration in the patient's condition.

N4: We know what our roles are, so if that emergency happens, we know what we're going to do. We are not going to "oh panicking, oh I didn't know", you've established "since you're looking after the machine you do this, since I'm looking after the patient I'll do this". There is no confusion between the two of them "no I have to do this, no you have to do that". You know what you need to do. (P. 4, Lines 153-158)

Generally interviewees reported good inter-professional collaborative working practices across the ICU team, for example, during ECMO retrieval, and knew that they could rely on the support of other colleagues when there were problems outside of the limits of their competence.

N1: I was quite anxious about it, because that was the first time doing it, but my team, I know I've got the perfusionist, the consultant and the consultant from our partner hospital was also supporting us. (P. 18, Lines 658-661)

However, some participants noted the challenges of working in an unfamiliar environment and the absence of 'team spirit', in the sense that colleagues from other hospitals would not necessarily go out of their way to accommodate the needs of the retrieval team. There was a sense that this might have been due to professional envy, or because they had encroached into another professional's territory.

D3: Working in retrieval as well, working in places that you don't know. Because you have to go to various hospitals as well and sometimes you have to cannulate patients in an environment that you don't know at all. It's very stressful I think sometimes. (P. 8-9, Lines 293-297).

N4: At my last retrieval I was asking them for some equipment, because I didn't have it in my bag. They said "you should have told us that you need this and that you need that". Those sort of things. What I wanted to say to them was "we are here, it's a theatre, so if you don't have one, just tell me that you don't have one, that's fine". (P. 14, Lines 510-515).

N4: So that's the thing, because some of them are feeling intimidated, probably, I'm not so sure. Intimidated that we are going to go into their theatre and do stuff without their help. (P. 14, Lines 520-522).

Doctors also united on an intra-professional basis to tackle some of their most challenging clinical responsibilities, such as making clinical and ethical decisions

in relation to either the administration or withdrawal of ECMO. A collaborative approach was useful in the absence of any definitive guidelines around when or when not to administer ECMO and doctors talked of consulting more experienced consultant colleagues, who had experience of utilising ECMO for particular clinical presentations. This allowed for a diffusion of responsibility amongst a group of professionals, and provided a sense of safety and reassurance.

D5: I think with ECMO it has to be done collaboratively, because as I said, we don't fully understand it and don't fully know the answers. (P. 9, Lines 286-287)

D3: You are not deciding alone, and I think that's great. I think it's very reassuring. We discuss a lot together, so if we have a phone call and we don't know, sometimes it's not clear. Sometimes the patient is 100 years old and they have metastatic cancer, there is no question, but sometimes it is a bit more subtle. So we discuss and we try to find, you know. The ego is not prevailing and I think that's good. (P.4, Lines 132-138).

The negative impact of collaborative decision-making was evident in end-of-life/withdrawal decisions, where there was an expectation that colleagues should have a unanimous verdict about withdrawal, before doing so, because some colleagues wished to exhaust all treatment and investigative options before making the final decision. Both doctors and nurses talked of their frustration at witnessing the on-going suffering of patients and relatives in this context.

D4: There is a tendency to go with the person who says we should carry on.

I: Right.

D4: Difficult not to, but it is never my decision. I mean it may be me who would say "guys, I think we should stop", but that decision is not my decision.

I: Ok. What is the impact of that, so if there is one person who said "I think we should carry on" Is there ever a negative impact of that?

D4: Yeah. The negative impact is that you continue to torture the patient for another week and then everybody stops. Or two weeks or three weeks or six weeks. Until they can understand where they are. (P. 14, Lines 544-557).

### 3.2.2. The Divisive Nature of ECMO

The ICU in which this research was conducted had experienced huge upheaval as a result of ECMO, which had been highly divisive amongst the staff team.

In every day clinical practice, some participants talked of attributing a particular status to patients being supported by ECMO, impacting the level of attention that they gave those patients in comparison to others.

D5: I'm not saying I'm not attentive to the others, but when it's an ECMO patient you are making sure that you are analysing absolutely everything, because we do treat these patients as VIP's, a little bit. In the sense that they are the sickest patients in the unit and they are on a therapy that is associated with significant risks. (P. 15, Lines 512-517)

D4: They think that "oh the patient is on ECMO, that's it", that they become a special patient. But they are not particularly special. It just means that they are at one extreme of sickness, and yet they are not yet so sick that they might not benefit. So they are not necessarily the sickest or most likely to die of our patients. (P. 2, Lines 55-60)

Participants reported feeling concerned about the potential for being consumed by the technology and losing sight of the person whom they were caring for. This was evident from the way in which ICU staff used language to describe their work with patients, but also emerged in daily clinical practices.

D3: Sometimes we say "these ECMO patients" and not "these patients on ECMO". ECMO patient doesn't mean anything, it's just a patient who happens to be on this technology. (P. 18, Lines 624-628)



N4: I always make the point of looking at both the patient and the machine, because it's not just the machine, it's also the patient, which is more important than the machine. (P. 2, Lines 42-44)

At an institutional level, status was attributed to being an 'ECMO specialist', who had additional training and/or responsibilities and this created an artificial divide between the ECMO and ICU teams. Historically, a whole consultant workforce had left the trust, feeling that they had been underappreciated and constrained by the institution, leaving the future of the service in turmoil.

D4: Some of it was perception and some of it was reality, about what people were doing in their jobs, what people were being paid to do, how many hours people worked, how hard they worked. Then walking out and leaving our nursing staff. It was all for ECMO. It was all because they felt that they could build a bigger and better ECMO service somewhere else. That they weren't supported as consultants in their ECMO service. (P. 8, Lines 313-324)

Despite the successful rebuilding of the ECMO service, there were lingering concerns that the intensive care workforce might become divided again, with the creation of 'nurse specialists' and the implicit assumption that those selected to fulfil those roles were 'superior'.

D5: You have suddenly created a new group of specialist nurses.

I: Yes.

D5: And they've all been created quite quickly, so I don't know if that has caused any problems. Perhaps it has.

I: What have you noticed? What gives you that idea?

D5: I think because the nurses quite enjoy it, because it is an increased skill set for them. So perhaps others aspire to it. So perhaps it is positive in a sense, that those who aren't trained in ECMO are aspiring to it. It could be negative in the sense that some might think they are being overlooked.

I: Right, ok. So some people might have the opportunity to have the extra training and responsibility, but there are only a limited number of opportunities to do that work.

D5: Yes, yes. (P. 16, Lines 548-563)

D5: I've not seen it, but I wouldn't be surprised if there is perhaps, a slight ill feeling between some staff members because of that.

I: I just want to get a sense of what you mean, so jealousy?

D5: Yes, yes perhaps. (P. 16, Lines 545-548)

ECMO's divisiveness had continued to impact the staff team throughout the rebuilding process. Nurses grieved the loss of trusted and experienced consultant colleagues and new consultants felt the pressure of trying to fill their shoes, in the sense of gaining the trust of the nursing team, alleviating their anxieties and repairing rifts that had emerged, all within the context of high expectations to deliver good patient outcomes at an institutional and national level. Nurses felt that time would enable them to develop trusting relationships with their new consultant colleagues, in order that they could rely on their clinical abilities to lead the team and make good decisions for patients and relatives.

D3: I mean obviously there was a big sense of loss, the team stayed, the nursing team and I can still feel that. We went through processes that were very difficult. (P. 12, Lines 431-433)

D3: There is this emptiness and we need to fill this emptiness and we've all got expectations. You need to give your outcome and it should be good and you need to collaborate with other colleagues. It's extremely, extremely, extremely difficult. (P. 12, Lines 427-430)

N2: I think the nursing side on the unit is very much the same as it was before, not too much has changed, but I suppose it's not that you're just dealing with different doctors, which was quite hard on the nursing staff.

I: Yeah.

N2: To have a whole change of medical staff, and lots of doctors that we don't really know. We're not sure about their decision-making, because it's just developing that trust in them. (P. 14, Lines 535-542)

Whilst challenging, the development of the new service had brought with it opportunity for rebuilding and growth, to reflect on established practices and to explore new ways of working, for example, giving nurses more responsibility and autonomy. Ironically, working through the challenges of divisiveness seemed to be the process that had begun to bring the team together again and encouraged more collaborative working practices, which stretched beyond the institution itself, for example, in the co-delivery of ECMO retrieval.

D3: Building a new team I think is quite positive. Changing practices, because I think the practices were very established, with relatively established consultants who have been working this was for a few years and it was working well, so why change? Now we are revisiting it. We are asking ourselves "was it good, or not?" "Shall we do it differently? Or not?" So dismantling and rebuilding something. (P.15, Lines 526-531)

D1: I prefer looking after my part of that patient care with the current style, of more nurse involvement. It's more collaborative, it's more susceptible for thinking about the communication aspects of it. (P. 19, Lines 676-679)

D4: For us as a trust, the development of, not just cross-site working, which could have been better but is now better than it was. But actually working with consultants from other areas. Other hospitals. (P. 10, Lines 381-384)

### **3.3. Riding the Emotional Rollercoaster**

Working in intensive care involves caring for some of the sickest patients and ECMO lies at the extreme end of a spectrum of caring practices developed to save lives. Doctors and Nurses described in detail their emotional responses to their work in this context.

### 3.3.1. Extremes of Life, Death and Emotion

Participants considered that care at a specialist ECMO centre provided the last bastion of hope for recovery, for the sickest patients and their relatives. Staff tended to adopt a humble attitude, and attributed successful outcomes to the brilliance of ECMO, rather than anything that they had done to 'rescue' the patient.

N5: I always remember this relative and he said "when your team arrived, you were like the superheroes with the capes". You have that kind of aura, like "here comes the dream team!" (both laugh). We don't want to be like that, but at the same time, we give some hope. (P. 21, Lines 735-739)

D2: We went to one of our local hospitals last time and there was a lady who had been in cardiac arrest for fifty minutes. She was still in arrest, so we put her on VA-ECMO and the brain was still fine. She's now eating and drinking without any respiratory support, she will go through a cardiac transplant. But she was arrested and dead for fifty minutes.

I: Yeah.

D2: So I mean it does great things, I think it's brilliant. (P. 2, Lines 78-86).

When caring for patients with severe cardiac or lung problems, there were no guarantees of success and patient outcomes were often stark: miraculous recovery or death. Commonly, patients being offered ECMO were young adults with a sudden onset of severe illness, such as H1N1 flu. Many participants felt that the stakes were higher for younger patients and became more invested in their care. They described stronger emotional responses, which may have related to the fact that these patients had life snatched away from them when they still had so much left to experience, for example, the opportunity to raise their own children.

D1: When something gets so polarised, that when it goes well they recover and go home and go back to normal health, or they have a complication

and die, it just feels to me like it makes it more, challenging. (P. 8, Lines 275-278)

D1: So a lot of them had a baby, got flu, got put on ECMO and as was often the case, her lungs were rapidly improving. We were congratulating ourselves, how quickly and how impressively she was getting better and then pupil dilates, other pupil dilates, CT scan confirmed, and she was brain dead.

I: So it can be very mixed feelings. It can be from elation to despair.

D1: Yeah. (P. 8-9, Lines 300-308)

The nursing team in particular talked of developing close relationships with relatives and providing support in the context of their emotional response to changes in the patient's condition. The withdrawal of ECMO represented a shattering of relatives hope and acceptance that their loved one was gone. Being in the presence of this experience at the end-of-life evoked the strongest emotions amongst nursing staff, who described a lingering sense of sadness and emotional exhaustion. Doctors and some nurses were reported to be avoidant of this context, because it was so emotionally overwhelming.

N4: Also seeing them, if they've already accepted that there is nothing that can be done and then all of the family will be there and letting the patient go. Oh, I hate that part as well, because you really see them crying and you really see them at their lowest point in life. I don't like that. It's so hard eventually seeing them like that. (p. 8-9, Lines 311-315)

N2: On those days you do leave work and you do feel emotionally drained, it's a very hard day. It will often be a day where you will have been on the verge of tears, because it's just impossible not to be. I think when the doctors and the other nurses in that situation, they know that that's the situation that is going on, but when you're that one nurse that's at the bed with the patient, with the family, it can be quite stressful and overwhelming.

I: Yeah.

N2: With all patients, but with ECMO patients especially I suppose. (P. 7, 263-272)

N2: We withdrew and I really did feel like the doctors had just vanished. The family were ready, they were all very ready. The wife was. I felt like the doctors just wanted me to turn the ECMO off for them, but I was like “I can’t, I’m a nurse, I can’t be the one that turns this off”.

I: Yeah.

N2: “You have to come in here and tell the family that this is, that we’re doing it now. I don’t feel like I have the clinical responsibility to actually withdraw the treatment on my own”. So, the doctor did just come in and did it, but then just walked away. (P. 11, Lines 394-403).

Some doctors implied that they experienced particularly strong emotional responses to traumatic events associated with medical decisions that they had been part of. For example, consultants often utilised ECMO with the intention of saving the life of a patient in imminent danger of death, such as in the case of administering ECPR (VA-ECMO). However, after the decision had been made to apply ECMO in these circumstances, some patients did not receive the hoped for outcome of life, or a dignified death. Participants talked of a sense of impotence, and feelings of anger, disappointment and regret at not being able to provide any kind of favourable outcome for the patient or their relatives and, would have lingering doubts about whether they should have taken a different course of action.

D3: I said “isn’t it futile”? I raised this, they said “he’s on the transplant list, he had a cardiac arrest, we should proceed”. We proceeded and it was just terrible I think. He died in the next few hours. We transferred him to our hospital, it was one of the worst transfers, he was bleeding, he was really unstable, he had lots of blood products. I don’t think someone should die in this sort of condition. I think it’s really disgraceful. (P. 9-10, Lines 330-337)

In contrast, some doctors held the perspective that putting patients on ECMO was very much the last throw of the dice, that they had done everything humanely and mechanically possible to save them, and therefore there was nothing more that could have been done. This acceptance of the idea that 'you win some, you lose some', may have been protective against feelings of guilt or self-blame relating to patient deaths.

I: I'm getting the sense that there is acceptance that that is part of the work?

D5: Acceptance, yes that's exactly it. Well with respiratory, perhaps three out of every 10 are going to die. With VA support, cardiac support, the mortality rate is much higher. So perhaps more than 50% are going to die. (P. 12, Lines 423-428)

D5: I do sometimes bring the work home with me. There are some patients, as I have eluded to before, that get to me more than others.

I: Yeah.

D5: It is very hard to predict the, I mean, of course the young ones, the young adults, or teenagers. Those ones certainly.

I: Yeah.

D5: But again, usually I'm comforted by the fact that, I know that they are being offered the extreme levels of support.

I: Yes.

D5: And that there probably is nothing that can be done, that isn't. (P. 13, Lines 446-456)

Patients and relatives were invited to the intensive care follow-up clinic after discharge from the unit, where they were able to meet the staff that cared for them. Despite having seen recovery of the sickest patients many times, participants remained surprised at the power of recovery and the transformation of patients, from a sick and incapacitated state, to living a full life with their loved ones. Baring witness to this held great significance for the staff team, who described the process as providing a sense of pleasure, achievement and

meaning, which stemmed from understanding the difference that their work had made.

D3: Still being a very sick patient. Sometimes you see them as a patient and not as a human being. But you understand from the family that they have got history, they have got a life, they've got family around, and they've got friends. Everything is built beyond that. You see almost the perspective, but not the first part of the picture. (P. 18, Lines 634-639)

D3: When the patient comes back and they are better, you see the first part of the picture and everything linked together. It's really powerful and you think you have helped a great deal, because obviously lots of the people wouldn't have survived without it.

I: Yeah.

D3: It just comes to great meaning when you see someone come back to life, who is technically almost dead. (p. 18-19, Lines 658-662)

N4: We had this case where we had a Sixteen-year-old only child, put on ECMO and he was bleeding. During that critical time, the doctors had spoken to the family and told them that he will not make it through the night. Low and behold he is alive! He is walking and he is going back to school. (P. 7, Lines 238-242)

### 3.3.2. Managing Emotions

Interviewees talked of a variety of ways that ICU staff managed the intense emotional experiences associated with working with ECMO.

Nurses expressed differing views about how emotions should be managed within context of supporting relatives at the end-of-life. Some felt at ease with expressing their sadness in front of relatives, and sharing in this emotionally intimate moment might have demonstrated their affection for, and attachment to the patient and family. Other nurses felt that sharing emotions could further burden relatives when they were most vulnerable, which was at odds with their desire to be supportive and containing. Some nurses suggested that they



possessed a sense of emotional resilience, which enabled them to cope with and detach from the emotional aspects of their work and get on with providing support.

N1: Sometimes you really have to control your emotion. I think sometimes you don't have to, I think if you feel like you want to cry, just cry! I think It's normal, it's human isn't it?

I: Yes, of course. I agree, I think it's normal to express yourself in that way. Do you do that in front of relatives, or staff?

N1: I think so, I think then they can see that you are crying as well. You can't hide that you are upset.

I: Yes, there's usually a sense you feel you want to.

N1: If I feel I want to go out, then I do, but sometimes, it's ok. You stay there and you are upset, but you are ok to be there, that's fine for me too. (P. 14-15, Lines 506-514)

I: Do you show your emotions at all to relatives?

N4: As much as possible no, because if you show your emotions, they are already struggling. They will be struggling more if they see you crying with them, so as much as possible no. There are instances where you can't hold it any more. If that happens, I just go out. (P. 9, Lines 330-333)

N2: Often when that decision is made to withdraw treatment, extended family, lots of people are coming in. It's obviously very emotional and you do find it hard not to get upset. I've always just thought that you have to separate from the fact that it's not your family member, it's not, and just do everything that you can to make it as easy as you can for them. (P. 7, Lines 254-260)

There was a general acceptance that staff had different ways of dealing with their emotions and members of the team were able to adapt in order to support their colleagues' needs. Some chose to express their emotions alone and appreciated colleagues giving them the space to do so by taking over their duties at the bedside. Others felt more comfortable venting their emotions to close colleagues,

who would often willingly support them. This informal support was common on an intra-professional basis amongst nurses and some doctors

I: Frustrating situation.

N1: Yeah, so I was upset that day.

I: When you get upset, or express emotion, do you feel that you are able to do that with the team?

N1: No, I went out and I cried in the corner.

I: Yeah.

N1: My colleagues saw me and said “oh, do you want to get out of here?”, “yes please, just stay with the patient for me”. That was it.

(P. 14, Lines 494-501)

N3: Some of them will talk about being a bit stressed, or this or that. These kind of things. They’ll bring it up.

I: Yeah.

N3: I’ve seen one or two crying before, but not all of the time.

I: Yeah. How do people support each other if they are expressing emotion like that?

N3: I think they do support their colleagues by the bedside. They do quite a lot of talking. I think just talking and bringing it out in emotions, just listening to them. It helps. But I think a lot of them just listen. (P. 13, Lines 471-480)

The willingness to express emotion amongst colleagues was influenced by cultural norms and some British doctors were seen as stoic figures that did not express their emotions or vulnerability. This intersected with the professional expectation that doctors should appear composed and in control, despite the unpredictable nature of caring for patients being supported by ECMO.

I: Yes. Do other staff talk about or manage the challenges in different ways?

D5: I’m not sure. I mean, I don’t really discuss it with others really.

I: Yeah.

D5: I'm typically English, I don't really talk about my feelings so much. (P. 13, Lines 429-434)

D2: I think there is a really different approach in the UK compared with Italy. So in Italy we are much more open, so we say what we think, all the time. Here in the UK a consultant needs to be just above everything and needs to always show that he's in power. Most of the time he doesn't show the time the challenges that he's experiencing, just because he needs to look very secure I would say. (P. 11, Lines 383-388)

Formal support was available to staff to meet their emotional needs in the form of team days, reflective groups and debrief sessions, some of which were facilitated by psychologists. On the whole participants found formal spaces to be helpful, as they provided a space to share and normalise difficult feelings.

N5: So we have nurse team days. We have that opportunity to just 'voice out', and share in the group. In a way it helps to listen to other people and share what they feel as well. You realise that you are not the only one who is feeling it. (P. 14, Lines 503-507)

There was a sense that some of these sessions were difficult to access or organise due to structural barriers and demands, such as staffing resources. Many of the participants called for debriefing in particular, to be integrated into their practice on a regular basis, following their involvement with a traumatic patient.

N1: When are we going to do it? That would mean, that myself and the nurse would be taken out from the bed space. Who will be looking after the patient while we are away? Do we have enough staff to cover us? Will doctors be available to talk that day? (P. 10, Lines 334-339)

D5: Perhaps patients that died unexpectedly, younger patients perhaps. I think there should be some formalised way, where we can all just chat about it.

I: Why do you think that doesn't happen at the moment?

D5: I think no formalised time, or place, or structure is set up for doing that.

(P. 14, Lines 469-474)

Some consultants saw official forums for emotional expression as the domain of junior professionals and less applicable to themselves.

D4: Oh, for the nursing staff they have debrief sessions, they have resilience training. That is open to our junior doctor staff. (P. 16, Lines 602-603)

## **4. DISCUSSION**

The initial portion of this section will consider the main research findings and provide a more nuanced analysis of the way in which they relate to the identified research questions and contribute to the academic literature in intensive care and ECMO. The chapter will then focus on the clinical and research implications of this thesis, give consideration to its limitations through a detailed critical review and conclude by summarising its main purpose and findings.

### **4.1. Main Findings**

Participants discussed a broad range of professional, ethical and clinical practice issues in their interviews. Broadly, doctors suggested that the most difficult aspects of their work related to the ethical and human side, involving decisions relating to: the administration of ECMO to patients for whom its efficacy was unclear, considering when to continue with or withdraw ECMO support, and conveying technical information and clinical decisions to distressed relatives. Amongst nurses, key challenges related to: establishing the limits of their competence and adapting to the new demands and expectations of their role in relation to supporting relatives at end-of-life and new technical responsibilities.

Three themes were identified from analysis of the interview data, which each related to the challenges identified above. 'Embodying the ECMO Specialist' referred to doctors and nurses feeling skilled and de-skilled in particular facets of their roles and the way in which learning supported competence development. Participants had a strong internal drive to improve the outcomes of services and their own practice and experienced a sense of pleasure and mastery from working in an expert field.

'Team dynamics' referred to the way in which the team often came together to manage challenge, for example doctors made medical decisions collaboratively, whilst nurses rallied together to manage technical emergencies and to meet the needs of patients requiring complex care. Historically, ECMO had also been a divisive force within the institution that the research was conducted, leaving

nurses feeling abandoned and unsupported by their consultant colleagues, and new consultants feeling the strain of living up to high expectations to perform. 'Riding the emotional rollercoaster' considered the way in which participants' experienced intense emotions when faced with positive or negative outcomes of their patients, and the responses of relatives. Nurses appeared to be more at ease with sharing emotions, whilst doctors tended to control their emotions on a personal level.

This study aimed to understand doctors' and nurses' conceptualisations of the key ethical and clinical practice issues associated with their work with ECMO, and the psychological impact of managing them. In order to answer these research questions more adequately and extensively, the themes will be discussed under a series of headings that seek to provide a fuller understanding of the underlying structures and processes that drive them, and any crossover between them.

#### 4.1.1. Adapting to Differing Conceptual Frameworks

Study participants had difficulty balancing the range of technical, human and ethical skills required in their roles. They experienced tension between feeling able to master some skill domains, and feeling inadequate in others. This feeling of mastery and inadequacy appeared to relate to the challenge of adapting to, and applying differing conceptual frameworks from those traditionally privileged by their respective professions as 'doctor' or 'nurse'.

*4.1.1.1. Adapting to a framework of technical and clinical responsibility:* ECMO nurses in this study had taken on more advanced technical and clinical responsibilities in relation to autonomous management of patients, the ECMO machinery and the facilitation of ECMO retrieval. Bucknall and Thomas (1997) suggest that nursing professionals commonly seek to attain more power and autonomy in order to gain a sense of fulfilment and job satisfaction, but such responsibilities may also present challenges, because they fall outside of the tasks and competencies commonly associated with nurses' 'caring' role.

Nurses in this study enjoyed the sense of autonomy in their roles and felt more confident and empowered when undertaking technical tasks that they were familiar with, as has been noted in other studies documenting the experiences of ECMO nurses (Corley et al., 2010; Honey and Wang, 2012). However, additional technical and clinical responsibility came at a cost. Many of the nurses felt anxious when encountering new and challenging clinical scenarios and overwhelmed by the level of responsibility and expectation placed upon them. Others were concerned at the level of risk and responsibility associated with managing technical emergencies and had difficulty determining the limits of their competence. These findings echo those of Alasad (2002) and Silva and Ferreira (2011), who found that ICU nurses felt anxious and de-skilled when dealing with new and challenging clinical scenarios involving life-saving technology. They suggested that the only way to overcome their fears was to gain more experience, an idea that was also expressed by participants in this study.

Nurse participants in this study described adapting to and managing these challenges through 'team spirit', as opposed to experience alone. For example, during technical emergencies with the ECMO machine, nurses tended to come together to troubleshoot the problem if no other experienced staff were available. Nurses also felt a sense of safety in knowing that more technically trained professionals such as doctors and perfusionists were on hand to provide support and bare some of the responsibility for managing the situation. This notion of coming together as a team and sharing expertise is a pattern that has been observed amongst general ICU teams and groups of specialist ECMO nurses (Corley et al., 2010, Honey & Wang, 2012; Wahlin et al., 2010).

4.1.1.2. *Adapting to an ethical and human framework:* The training and expectations of doctors in intensive care and ECMO tends to be driven by technical concerns, and this was reflected in participants' description of the focus of formal training being on such aspects (e.g. simulation), rather than more abstract ethical and human facets of their role (Valentin & Ferdinande, 2011). This is in line with ECMO literature, which is replete with articles relating to the training of practical and technical skills [e.g. Brum et al. (2015)], whilst it is also

well documented that doctors have less than adequate training in areas such as breaking bad news to relatives (Quill & Townsend, 1991).

Doctors in this study felt more confident and accomplished when applying skills from a technical knowledge and skills framework to which they were well acquainted, for example, successfully cannulating a patient. However, other aspects of their role were far more underdetermined and doctors had difficulty understanding 'the rules' of complex ethical decision-making in the absence of a clear framework. For example, the lack of any clear guidelines for deciding whom ECMO should be administered to, was associated with the dearth of research evidence, the application of differing selection criteria across cultures, conflicts with personal values, and the unpredictable nature of clinical outcomes (Crow et al., 2009). Deciding when to withdraw ECMO was a similarly 'messy' process, because it involved 'second guessing' the wishes of patients in the absence of their ability to partake in discussions, and any advanced directive documenting their wishes. Such decisions were further confused by clinicians' own values and the views of relatives.

'Messy/abstract' skills were more difficult for doctors to learn because they represented skills from a different, less familiar conceptual framework. Doctors therefore lacked confidence in their ability, because the process associated with achieving a good outcome was less predictable, whilst 'good outcomes' were also less tangible than those associated with the technical framework. For some physicians the 'messy' and abstract nature of medical decisions appeared to provoke moral distress, where they experienced a lingering sense of guilt (known as moral 'residue') about whether they had made the 'correct' decision, (Epstein & Delgado, 2010).

The difference in doctors' and nurses' comfort with technical and human tasks may in part link to the types of individuals that are attracted to professions that are seen as either 'treating' or 'caring', and the kinds of knowledge and skills that are privileged in the training designed to fulfil them (Flannery et al., 2016). Participants considered that structured and 'on-the-job' learning provided opportunities to develop abilities in both familiar and unfamiliar conceptual



frameworks. For doctors this involved participating in frequent case discussions and reflecting on clinical and ethical aspects of their work. For nurses it involved more exposure to new tasks and responsibilities such as those involved in the facilitation of ECMO retrieval, and attending structured training days (e.g. simulation).

#### 4.1.2. Psychological Management in a Context of High Emotion

Participants from both professions talked of experiencing intense emotions when witnessing patient recovery, deterioration and death. Many expressed that they felt the strongest emotions towards young adults that were critically ill and a number of the participants were themselves young adults. This parallels the findings of Corley et al. (2010), who suggest that caring patients on ECMO who have similar attributes to staff, could hold particularly strong emotional resonance. Positive emotions such as pleasure and reward were most evident when doctors and nurses in this study witnessed or heard of the recovery of patients that they had cared for. This replicates the outcomes of other interview studies with critical care staff, and emphasises the importance of providing staff with opportunities to connect with stories of patient recovery through involvement in follow-up interventions, such as intensive care follow-up clinics (Anolhe et al., 2015; Wahlin et al., 2010).

The kinds of situations that caused distress for doctors and nurses were very much intertwined with their roles and responsibilities. Nurses' distress was commonly grounded in the relational side of the work, for example supporting families at the end-of-life, whereas doctors' distress often related to decision-making.

4.1.2.1. *Defences against moral distress and high emotion:* A number of authors have documented the deployment of psychological defenses by health care staff, as a means of managing the systemic and emotional demands of institutions such as hospitals (Loxley, 1997; Menzies-Lyth, 1988; Obholzer & Zagier Roberts, 2003; Regan 2014). Menzies-Lyth (1988) observed defensive practices amongst nurses working in a hospital setting, depersonalisation of patients, diffusion of accountability for patients' welfare and cumbersome decision-making processes.

These were said to protect against overwhelming feelings of anxiety and distress associated with systemic and resource constraints, and an inability to meet the physical and emotional needs of patients and relatives. Loxley (1997) suggests that unconscious defences at the individual, team and institutional level help healthcare staff to continue to function in spite of their feelings of anxiety.

'Immature defences' such as avoidance, blaming, denial or projection of difficult feelings can have a detrimental impact on relationships with patients, relatives, other healthcare professionals as well as the well-being of the staff members utilising them. Regan (2014) reports that such defences are frequently adopted by healthcare staff working in palliative care and end-of-life settings due to the distressing nature of the work. For example, during conversations with patients receiving palliative care, healthcare staff may avoid topics that they believe lead to distress or anxiety, such as those relating to death. Although there is limited research considering the impact of the use of defences in ICU settings, Regan, Howard and Oyeboode (2009) have noted an association between their long-term utilisation by ICU nurses (as a means of coping with the emotional demands of such situations) and emotional exhaustion (a facet of burnout).

Doctors in this study employed a range of psychological defenses that buffered the potential for experiencing distress in relation to decision-making. They frequently made complex decisions collaboratively, which involved seeking the opinion of close/more experienced colleagues or the broader MDT. Reznik (2006) describes this process as the diffusion of responsibility, and suggests that ICU doctors may employ this strategy in the face of an unfavourable or uncertain outcome, to alleviate themselves of blame and responsibility. Benson (1984) has identified two key problems with this approach. 1) It can make it difficult for relatives to engage in the decision-making process because of the broad range of professionals involved. 2) It has a tendency to further complicate and delay the process of decision-making, as clinicians often seek a unanimous decision, and in such circumstances ECMO acts as a 'bridge to nowhere' (Abrams et al., 2014). This prolonged patient suffering led to a redistribution of distress amongst the team, particularly amongst nurses who had most frequent day-to-day contact with the patient. Similar findings have been reported by several authors, who suggest that staff are likely to experience moral distress if they were asked to care for

patients within such contexts (Harris, 2002, Kinedinst et al., 2017; Raza, 2017; Williams & Dahnke, 2016). This is particularly pertinent to ECMO nurses, whose moral and professional values favour withdrawal and providing a dignified death, over prolonging futile intervention (Harris, 2002).

Another psychological defense applied by doctors was the idea of 'rationalisation'. Doctors regularly dealt with patient deaths, particularly those supporting patients with VA-ECMO. 'Rationalisation' involved weighing up the odds of patient survival and coming to the conclusion that patients being offered ECMO were very much drinking at the last chance saloon. 'Rationalisation' therefore mitigated the emotional response when patients did not recover, allowing doctors to feel as though they had done all they could for patients. Personal accounts also suggest that this protective 'rationalisation' of outcomes is a strategy deployed in other professionals such as neurosurgeons, who similarly have to manage the responsibility of trying to save patients' lives when they are critically ill (Kaloostian, 2013).

*4.1.2.2. Professional status, power and emotional expression:* Supporting patients and relatives through the end-of-life presented one of the most emotionally challenging contexts for nurses. There was a culture of turning to colleagues in the nursing team for informal emotional support when feeling overwhelmed, although, not all nurses chose to do so. Nurses expressed conflicting views about the acceptability of expressing emotions in front of relatives in this context. Efsthathiou and Walker (2014) note that locating the personal, professional and emotional boundaries with patients and relatives in such circumstances represents a significant difficulty for nurses. Some nurses may have chosen to limit the extent of emotional expression in front of patients, because doing so too regularly might become wearing and lead to compassion fatigue or burnout (van Mol et al., 2015)

Doctors on the other hand rarely expressed emotion or vulnerability to colleagues and tended to manage their emotions privately, portraying an image of being in control within the context of great clinical uncertainty. Halpern (2003) suggests that detachment enables doctors to continue to provide good quality care to

patients in the face of emotionally charged circumstances. Emotional detachment was one way that doctors manifested their power as consultants and may have provided an important function to the team, helping them to feel more confident in consultants' abilities (such as making-decisions) when patient outcomes were unpredictable (Shapiro, 2012).

Nurses reported that doctors tended to avoid being present at the end-of-life with patients and relatives, mirroring the findings of other research examining ICU professionals roles in end-of-life care (Efsthathiou & Walker, 2014). Their avoidance of such emotionally charged contexts might have represented a concern about being unable to contain their own emotions and their reluctance to relinquish power (Shapiro, 2012). For this reason, consultants also tended to avoid emotionally based reflective groups, considering them the domain of nurses and junior doctors. However, the call for more regular debriefing sessions from a range of participants, including doctors, provided an indication that they hoped to be able to talk about strong emotions in the context of traumatic and upsetting events and seek reassurance about their decisions and clinical actions, even though this was at odds with professional expectations. The challenge therefore may be to provide such spaces in a way that they feel safe for doctors to access.

#### 4.1.3. Consequences of the Drive to Achieve Greatness with ECMO

The personal sacrifices of staff working in ICUs are well documented, in that they frequently experience burnout and fatigue. These problems are often attributed to the systemic demands of working in the ICU, such as long working hours, shifts and staffing pressures (Argent et al., 2015; Dall'Ora et al., 2015). Participants talked of making similar personal sacrifices, and the impact on their health and family life, which was driven in part by systemic pressures, such as the need to produce outcomes and data that demonstrated a high level of care. However, interviewees provided some novel insights into personal factors that drove their decision to make such sacrifices in the context of their work with ECMO. Their professional drive appeared to be closely related to the sense of reward they experienced from feeling as though they were innovators, working at the forefront

of medicine. Staff may have hoped that their sacrifices would drive up standards, save lives and improve their own clinical abilities.

Gilbert (2009) describes an affect regulation systems model, in which three affect systems drive human behaviour: drive/excite, threat/protect and contentment/soothing. Staff working with ECMO may be more prone to 'overstimulation' of the drive/excite affect system, which provides feelings of pleasure and arousal when goals are achieved. This system cannot provide a sense of long-term contentment, hence the drive to continue to work harder and strive to achieve more in an attempt to appease it (Gilbert, 2010)

The finding that ECMO can be divisive amongst ICU teams is novel, in the sense that it has never been explicitly expressed in another study. However, literature in the area does provide a hint of emerging divides in other institutions. For example, some tensions were noted amongst ECMO and non-ECMO nurses working in Australia and New Zealand, where those who were ECMO trained, considered that they should be rewarded with higher salaries due to their increased specialism and responsibility (Corley et al., 2010, Honey & Wang, 2012). Gilbert's (2009) affect regulation model provides some explanation for the way in which ECMO might lead to division and difficult team dynamics such as those documented in this research, whereby overstimulation of the drive/excite system (in the same way as noted above), perhaps led to the desire to create a "bigger and better ECMO service somewhere else" and thus consultants leaving the trust.

#### 4.1.4. Relationship with Technology

Participants' relationship with ECMO was a central issue that cut across several of the identified themes. The ECMO technology was seen as having central role in patient care, clinical outcomes and team dynamics.

Across various domains of medicine and indeed intensive care, individual skills and competencies are often attributed to successful patient outcomes. These include performative skills such as the ability to master surgical procedures, and diagnostic skills, involving the identification of symptoms that are indicative of a

particular illness (Kneebone, 2016). Some participants in this study made reference to the idea of mastering particular technical competencies, such as successfully cannulating patients in the case of doctors, or being able to manage the interface between patient and machine and troubleshooting problems in the case of nurses. However these competencies were rarely talked of during the telling of stories of miraculous patient recovery. Instead, successful outcomes were often attributed to the brilliance of ECMO itself, rather than the skill of the clinician.

Medical professionals commonly overemphasise their own contribution (e.g. knowledge and performative skill) to successful clinical outcomes, a cognitive bias known as fundamental attribution error. This bias leads clinicians to overlook the contribution of external factors to the final outcome (Artino, Durning, Waechter, Leary & Gilliland, 2011). However, participants' attribution of success to the brilliance of ECMO was very much the opposite. One explanation for this tension is that that ECMO specialists have an internal locus of control for tasks that feel within their competence and are predictable (e.g. cannulation or service development) but adopt an external locus of control when outcomes are highly unpredictable, and in such cases, attribute the successful outcome to the technology itself (Rotter, 1966).

The importance that staff attributed to the machine was evident in the way that participants described clinicians use of language in clinical practice, for example, referring to their patients as 'ECMO patients' rather than 'patients on ECMO'. A discussion with one participant following their interview drew parallels with the attribution of importance to psychiatric labels and the way in which psychiatric professionals can be drawn into the trap of seeing the label but completely missing the person behind it (Timimi, 2014). Participants had also observed the impact of this on clinical practice, and were careful to give equal attention to the patient and the machine, rather than becoming overly focused on ECMO itself.

Externalising is a concept associated with narrative therapy, in which problems are de-coupled from people and can alleviate a sense of self-blame (Combs & Freedman, 2012). Participants had a tendency to externalise the divisions that

had occurred within the team, by placing an emphasis on the role of ECMO itself in causing the systemic tensions. This may have had a protective function, enabling them to alleviate any sense of self-blame or control over the process (Carthey, Leval & Reason, 2001). It may have also sustained 'team spirit' in the face of potential division in the future, by removing the blame from other individuals in the team.

#### 4.1.5. Summary of Findings in Relation to Research Questions

How do ICU doctors and nurses conceptualise the key ethical and clinical practice issues relating to their work with ECMO?

Doctors and nurses conceptualised the ethical and clinical practice elements of their roles with ECMO in different ways. Their thoughts about these issues were very much associated with their professional status and responsibilities. The clinical and ethical aspects were most challenging when they were at odds with doctors' or nurses' professional conceptual frameworks. For doctors this included 'messy' tasks such as decision-making and breaking bad news in which success was difficult to quantify, whereas for nurses the main challenge was to learn and apply new technical skills and responsibilities within challenging and high pressure circumstances.

An interesting relationship was observed between staff and ECMO, where ECMO provided opportunities to feel masterful and expert. However, in some clinical contexts, e.g. when patients had a slim chance of survival and staff felt out of control, positive outcomes were attributed to the brilliance of the technology.

What is the psychological and professional impact on doctors and nurses managing these issues?

In order to sustain status and power and the confidence of the team, doctors needed to be seen as being 'in control'. This involved containing their emotions and managing them independently. Doctors also deployed a range of psychological defenses to protect them from the challenging emotions associated with 'messy' aspects of their role, and at times, these could have a detrimental

impact on other professionals in the team. Nurses felt more confident in expressing their emotions to others in the nursing team, due to the strong sense of 'team spirit' and the widespread culture of providing informal support. 'Team spirit' also helped to alleviate nurses' anxieties relating to new and challenging clinical and technical responsibilities.

## **4.2. Implications for Clinical Practice**

The findings of this study have informed the following recommendations for clinical practice, which may be of use to intensive care teams working with ECMO.

### **4.2.1. Encouraging Teamwork and Preventing Division**

Teamwork is an important aspect of providing intensive care, and institutions offering ECMO should take heed of the finding that ECMO could unite and divide teams. Institutions may therefore wish to encourage practices that galvanise 'team spirit', for example the dissemination of patient recovery stories amongst staff. An awareness of the divisions that ECMO can cause is also of use, in the sense that they may be identified at an earlier stage, and the reasons behind them discussed as a staff team to prevent resentment amongst staff and fragmentation of teams. The institution in this study was preventing further division by ensuring that continuing professional development opportunities, such as the discussion of clinical cases relating to ECMO, were open to both ECMO and non-ECMO staff.

### **4.2.2. Developing Skills in the Communication of Sensitive Information to Relatives**

The finding that participants felt underprepared and undertrained to communicate sensitive emotional and technical information to relatives, suggests that there is a need for the development of training and supervision in this area. Bakarar (2007) provides a framework for the development of interpersonal skills that may be useful to consider in order to develop doctors' confidence and abilities in this respect. Specialists might utilise a variety of self and peer evaluation methods in order to reflect on and develop their ability to communicate with patients and



relatives, for example: direct observation and feedback from peers and audio or video recording of family discussions so that they can be unpicked and discussed in supervision. These are commonly utilised practices in the training and supervision of therapeutic professionals, that frequently discuss highly emotive content with their clients (Padesky, 1996). Psychologists may therefore be well placed to provide consultation and to support the embedding of such practices into intensive care staff supervision, training and clinical work.

#### 4.2.3. Utility of Understanding Protective and Defensive Practices

This study documents the use of a range of protective/defensive practices employed by ICU staff, to prevent them experiencing moral distress. However, some of these practices (e.g. diffusion of responsibility) had potentially detrimental implications for the well-being of other professionals, relatives and patients. The understanding of these processes as elucidated in this research, may be of use to staff teams (or indeed psychologists working with them) experiencing high emotion or a sense of stuckness relating to life or death decisions, including the withdrawal of ECMO.

#### 4.2.4. Setting up Appropriate Support Systems for Staff

Participants talked of various ways in which staff expressed emotion when working within complex and upsetting clinical contexts and a number hoped for more formal support in this respect. It may therefore be useful to conduct a consultation with ECMO teams and more broadly with ICU staff to understand how their emotional needs can be best met. For example, many participants asked for more 'debrief', but were unclear about what this might entail and how it could be helpful to them. One suggestion is that they could provide an opportunity for emotional venting and containment, rather than an in-depth post-mortem of events, in light of evidence that the efficacy of structured debrief following traumatic events is contentious (Kagee, 2002). Some questions to consider when setting up reflective or debrief spaces might include: Should they be used to reflect on clinical events and actions, emotional venting, or do both go together? Should there be more of a focus on weaving in hopeful messages or solution focused approaches and connecting the team to positive aspects of care? How can they be made accessible for staff given the nature of their clinical

duties (e.g. being unable to leave the patient's bedside)? How can they be set up in a way that they respect cultural and professional differences in emotional expression and feel safe to access? Should reflective/debrief spaces be offered specifically to ECMO staff, or shared with other professional groups given what is now known about the potential divisiveness of ECMO?

### **4.3. Critical Review**

This critical review will broadly examine the robustness of the research methodology and findings from three perspectives: general research limitations, reflections on the research process and a structured quality assessment.

#### **4.3.1. General Research Limitations**

This research sought to obtain an extensive range of staff experiences of clinical practice associated with ECMO and consequently adopted a broad framework for the collection and analysis of data, in line with Braun and Clarke's (2006) recommendations for under-researched topics. As such, it covers a range of issues impacting ECMO specialist staff, but provides a less in-depth understanding of staff experiences of some specific ethically challenging contexts, for example the use of ECMO in organ donation, for resuscitation or in the case of a DNR order (Dalle Ave et al., 2016; Ramanathan et al., 2015). In addition, little consideration was given to the roles of patients and relatives in shared decision-making, an area of ECMO work that has increasing relevance, given that patients are more frequently conscious whilst receiving support.

In order to obtain a relatively homogeneous sample, this research only sought the views of doctors and nurses. However, there are a range of other professionals who work in specialist ECMO teams, including surgeons and perfusionists. Due to differences between the skills and competencies of the aforementioned professions, the views expressed by participants in this study are unlikely to be representative of all professions involved in ECMO care. In fact, the qualitative approach adopted in this study was limited in the sense that interviewee's responses only provided access to semi-rationalised retrospective accounts of abstract clinical experiences involving ECMO. These accounts are likely to have

been influenced by a range of confounding factors, including broader intensive care practices. Therefore, whilst many of the issues discussed during interviews were relevant to ECMO, they are not necessarily unique to ECMO. As such, it was not possible to investigate ECMO as a separate entity from the broader ICU.

This study adopted an interpretative approach to engage with and make sense of research material. These interpretations were supported by relevant theory and literature, but still represent a tentative understanding of doctors and nurses work with ECMO. As such, there may be many other ways of explicating the accounts given by participants in the study (Yardley, 2000).

#### 4.3.2. Reflections on the Research Process

Reflective logs were used throughout the research process to consider how various aspects might have been conducted differently. Gibb's (1988) reflective cycle was used as a structure, giving consideration to events that occurred, associated thoughts and feelings, an appraisal of the outcome of situations and consideration as to what could have been done differently. Smith's (2016) Social LA GGRRAACCEESS model was also used to consider ways in which aspects of my own identity or relationship to the research context, might have influenced ways in which the research was conducted.

4.3.2.1. *Recruitment Challenges:* The data collection process was challenging. It took six months to recruit the ten participants who took part. One key recruitment dilemma was that I had been advised by ICU staff that the easiest way to recruit participants was to try to 'catch them' on days that they had been scheduled on to the ECMO retrieval rota, because they would otherwise have difficulty leaving their bedside duties. However on five separate occasions interviews were cancelled or rescheduled due to staff being called to retrieve patients, or becoming caught up in caring for patients on the unit, significantly lengthening the recruitment process and reducing the amount of time available for completing other aspects of this research project. One way of addressing this may have been to build in a more flexible means of collecting interview data at the ethical approval stage. For example, many of the consultants had the ability to

communicate via video conferencing and arranging interviews in this way, may have made participating an easier process for interested staff members.

*4.3.2.2. Impact of ability, language, professional status and power on the interview process:* Power differentials are a common ethical concern for qualitative researchers, who are generally in a position of power when interviewing participants, particularly if they are from vulnerable groups. Researchers must therefore have an awareness of the impact of this on the research process, for example recognising when they are being drawn into a position of leading the direction of the interview (Allmark et al., 2009). In this study, many of the participants had considerable ability, expertise and professional status in intensive care medicine and interviews were conducted in their working domain. This served to reverse the power differential at different points in the interview process. For example, there was a sense that some ECMO consultants sought to push their own agendas, and at times I had difficulty interrupting and refocusing the direction of conversation, when responses became tangential or referred to general ICU issues.

Despite having a different training background from research participants, many may have assumed that I had a similar level of medical and technical knowledge and chose not to simplify their language during the interviews. In some circumstances this limited access to particular experiences. For example, when I attempted to open up a discussion about shared decision-making between doctors and relatives with one consultant, I was abruptly cut-off by a statement that suggested that I should have a good understanding of the concept. This prevented me from asking further questions on the topic for fear of looking as though I lacked knowledge. The power differential in this context may say something about interactions between consultants and junior professionals and/or patients or relatives in relation to topics such as decision-making, where the latter group of lower status or power may have difficulty questioning or challenging the decisions of the former, who hold the power.

My own professional status as a psychologist may have had an impact on the course of the interviews. When questioning participants I had a tendency to draw

on key therapeutic competencies such as summarising and reflecting back my understanding of the meaning of participants' utterances. Whilst Whiting (2008) considers these to be perfectly acceptable practices for semi-structured interviews, at times, my summaries and reflective statements had an interpretive tone, to which participants often responded 'yes'. It is difficult to know whether there was genuine agreement with these interpretations, or whether participants simply acquiesced due to my status as a psychology professional, who might have more 'insight' into their thinking, or due to the power differentials in the interview context. Prior interactions with two of the participants on placement as a trainee, may have had some effect on the content discussed in interviews, for example leading to an avoidance of highly emotive material.

*4.3.2.3. Impact of gender and physical stature on the interview process:* In Smith's (2016) model, gender and physical stature are described as factors that can influence interactions with others, eliciting particular behavioural responses. During the interview process I noted that three of the four male participants were less open to talking about their emotions, emotional vulnerability or the need to access emotional support available on the unit, for the challenging or traumatic aspects of their work. My physical presence as a tall well-built male may have implicitly impacted some male participants' openness to discussing emotional aspects of the work, in line with societal expectations relating to stoicism and masculinity. Schwalbe and Wolkomir (2001) report that cultural expectations relating to masculinity can impact male responses in this way, during research interviews.

*4.3.2.4. Impact of professional status on research methodology:* My status as a trainee psychologist that has been educated within a western university context is likely to have been influential in my choice of adopting a critical realist epistemological stance and research questions that required data to be interpreted in order to answer them. This is because much of my core therapeutic training (e.g. Cognitive Behaviour Therapy) is based on the assumption that there are common underlying psychological processes that drive individual and group behaviour and that these can be accessed and understood by someone with the appropriate expertise [e.g. a psychologist] (Marsella, 2013). One criticism of this

approach is that it may not be accessible or fit with the knowledge framework of the people whom this research is most applicable (ICU professionals), and therefore careful consideration will need to be given to the way in which research findings are presented when disseminating more broadly in the medical community (Willig, 2012).

#### 4.3.3. Appraisal of Research Quality

The Centre for Reviews and Dissemination [CRD] (2009) state that there are a plethora of criteria available for assessing the methodological quality and credibility of qualitative research, but suggest that there is no agreement about which have most utility. In the methodology section of this report there are some preliminary discussions about the way in which the credibility of this research was established, using a simple framework described by Noble and Smith (2015). In this section, The Critical Appraisal Skills Programme [CASP] (2017) checklist was used to provide a more extensive assessment of the methodological quality of this study. The CASP (2017) checklist was chosen because it is one of the few structured tools available that have demonstrated sufficient rigour for assessing the quality of qualitative research to a level sufficient for systematic reviews. It was also a familiar tool to the researcher, who had previous experience of utilising it (CRD, 2009). Aspects of the quality of this study are discussed using the ten broad criteria in the CASP tool, under the six condensed headings below.

*4.3.3.1. Adequacy of design and data collection:* This research provides a brief but adequate description of its key aims and chosen research design. The chosen qualitative design was appropriate for this study, given that little was known about staff experiences of working with ECMO and that previous accounts in the academic literature were either highly specific (e.g. Harris, 2002), or brief and lacked nuance (Corley et al., 2010; Honey & Wang, 2012). Justification was also provided for the use of semi-structured interviews for data-collection and the methods used to conduct interviews and store data were clearly described and grounded in literature, with appropriate documentation evidenced (e.g. interview schedules). The recruitment of participants with more extensive experience of working with ECMO was appropriate, given that they were likely to have more experience and an in-depth understanding of several facets of this work.

Consideration was given to the reasons why some participants were not able to take part due to constraints in their working roles, and suggestions are made for adaptations to future research to accommodate them. The research used conceptual depth criteria as a means of determining when enough quality interview data had been collected, in order to provide a sufficient analysis and the process of establishing conceptual depth is clearly described.

4.3.3.2. *Reflexive and ethical considerations*: A good reflexive account is given describing aspects of the researchers identity and how they might have influenced the design of the study and analysis of data. This report also provides an adequate summary of key ethical considerations such as the processes involved in obtaining informed consent, and ensuring anonymity and confidentiality of participants, with example documentation provided. The processes of university ethical review and R&D approval are also clearly described, and the fact that the study stood up to the scrutiny of these processes provides confidence that it is ethically robust.

4.3.3.3. *Rigour of analysis*: A detailed description of the transcription and analysis of data is provided, demonstrating a robust methodology. Thematic maps, a coding frame and a page of coded transcript evidence a detailed analytical process. Data (participant quotes) presented in the results attempt to retain some context, to show that they adequately support the assertions made, and tensions in the data are explored. Early coding and thematic development and the final themes and interpretations were discussed with the DoS, who acted as a second analyst, providing validation of the findings. Given more time, it may have been useful to add an additional layer of verification, to discover whether the description of themes adequately represented the data that had been coded into thematic categories. An independent analyst could have been asked code segments of data using the system adopted by the researcher, and subsequently compared with the researcher's analysis to check inter-rater reliability (e.g. Wellman, Szlachcic & Lepori, 2016).

4.3.3.4. *Statement of findings*: This research provides a range of explanations for findings and interpretations that are well grounded in existing research and

academic literature and discussed in the context of the research questions. Some tensions or counter-evidence for interpretations are explored in both the results and discussion sections, but a more detailed exploration of these in the context of academic literature may have made for a more robust discussion.

**4.3.3.5. *Value of the research:*** Implications of the findings are outlined and new areas for research discussed. The findings of this study have potential transferability and have particular relevance to ECMO centers and specialist trained ECMO staff. The findings may be of particular interest to centres in which nurses are becoming more autonomous, or are developing a new ECMO service. This research also has applicability to regional hospitals from whom patients are retrieved, by providing some insight into the challenges of specialist ECMO teams and the retrieval process. ECMO is a technology that is now being applied internationally. This research was conducted within a western medical context and it is unclear how transferrable the findings are to institutions embedded within other cultures (Marsella, 2013).

**4.3.3.6. *Critique of quality assessment:*** It should be noted that the quality of this research was self-assessed, and therefore open to my own biases. Given more time it would be useful to obtain verification of this quality assessment from an external party.

#### **4.4. Dissemination and Considerations for Future Research**

The findings of this research will be disseminated within the trust it was conducted, through a presentation at a specialist ECMO team meeting. Given the novel nature of this research, there are also plans to present an abbreviated version of this report in an academic journal and/or at an academic conference, to encourage further discussion and development of the issues raised.

Further qualitative research in this area might wish to consider ICU staff experiences of professional and/or ethical issues that relate to specific aspects of ECMO care that this study did not explore in detail. One example is the decision-making process that takes place between professionals and in some



circumstances patients and/or relatives. This is particularly pertinent as the practice of 'awake ECMO' in which patients are supported whilst they are conscious, is used more frequently. Ethnographic approaches might be useful here in order to obtain a first-person account of interactions between members of an MDT or staff and relatives during a family meeting, in which decisions are made and/or communicated (e.g. in relation to initiating or withdrawing ECMO). This could provide unique insights into the professional and power differentials at play during these interactions. A Foucauldian discourse analysis of recordings of such meetings might also be used to a similar end.

The use of quantitative methods such as surveys may have some utility for determining whether the views expressed by doctors and nurses in this study form more widespread patterns amongst the ECMO workforce within a national or international context. A survey study might wish to investigate perceptions of professional competence in differing areas of doctors' or nurses' clinical practice with ECMO, for example doctors' perception of their decision-making abilities or skills in communicating with relatives, or nurses' perspectives on their ability to manage ECMO autonomously.

There is also scope to evaluate any changes to clinical practice arising from this study, such as the recommendations relating to supervision, training and reflective practices in areas that participants identified needing further support, including the development of doctors' ability to communicate with relatives and the provision of accessible spaces for debrief.

#### **4.5. Concluding Remarks**

Staff working in ICUs are exposed to, and frequently manage a broad range of professional and ethical issues. This thesis specifically investigated intensive care doctors' and nurses' conceptualisations of the key professional, ethical and clinical issues working with ECMO, an advanced form of ICU life support technology. Doctors experienced most challenge with abstract aspects of their work, such as making decisions about when to utilise and withdraw ECMO and communicating complex information to relatives, whereas nurses often had

difficulty locating the limits of their competence when dealing with technical emergencies that endangered patients' lives. Often, these challenges were managed through collaborative intra and interdisciplinary working practices, such as groups of doctors deciding when ECMO should be utilised and withdrawn, and nurses and other health professionals working alongside each other to solve technical problems.

This study is one of the first in the ICU literature to consider the underlying psychological processes associated with work with advanced life-support technology its accompanying challenges. Collaborative working for example, often had a protective function. In the case of making difficult clinical and ethical decisions, it facilitated a diffusion of responsibility and therefore alleviated doctors' anxiety, but at times, passed on distress to nursing colleagues who supported patients and relatives through their suffering whilst decisions were made. Other underlying processes also highlighted divergence amongst the staff team, for example the differences in the way that emotions were managed and expressed by staff depending on profession, and the way in which a drive for specialism and the development of ECMO care could create tensions between ECMO trained professionals and other ICU colleagues.

This study has laid a foundation for further research into ECMO and advanced ICU technologies, which may wish to consider whether the professional, clinical and ethical issues identified by staff in this study are prevalent amongst a broader population of professionals working in this field. It might also further elaborate the processes involved in various clinically and ethically challenging facets of the work, such as decision-making and communication between staff, patients and relatives. From a clinical perspective, this study has generated a range of recommendations that may enhance staff well-being and support skill development with the goal of improving ECMO care.

## 5. REFERENCES

- Abdelbary, A. (2017). Nightmares during ECMO run. *Qatar Medical Journal*, 1(1), 1–2. doi: <https://doi.org/http://dx.doi.org/10.5339/qmj.2017.swacelso.47>
- Abrams, D. C., Prager, K., Blinderman, C. D., Burkart, K. M., & Brodie, D. (2014). Ethical dilemmas encountered with the use of extracorporeal membrane oxygenation in adults. *Chest*, 145(4), 876–882. doi: <https://doi.org/10.1378/chest.13-1138>
- Alasad, J. (2002). Managing technology in the intensive care unit: the nurses' experience. *International Journal of Nursing Studies*, 39(4), 407–413. doi: [https://doi.org/10.1016/S0020-7489\(01\)00041-4](https://doi.org/10.1016/S0020-7489(01)00041-4)
- Alhojailan, M. I. (2012). Thematic analysis: A critical review of its process and evaluation. *West East Journal of Social Sciences*, 1(1), 39-47
- Allen, S., Holena, D., McCunn, M., Kohl, B., & Sarani, B. (2011). A review of the fundamental principles and evidence base in the use of extracorporeal membrane oxygenation (ECMO) in critically ill adult patients. *Journal of Intensive Care Medicine*, 26(1), 13–26. doi: <https://doi.org/10.1177/0885066610384061>
- Allmark, P. J., Boote, J., Chambers, E., Clarke, A., McDonnell, A., Thompson, A., & Todd, A. (2009). Ethical issues in the use of in-depth interviews: Literature review and discussion. *Research Ethics Review*, 5(2), 48-54.

American Association of Critical-Care Nurses. (2008). Position statement: Moral distress. American Association of Critical-Care Nurses. Retrieved from [http://www.aacn.org/wd/practice/docs/moral\\_distress.pdf](http://www.aacn.org/wd/practice/docs/moral_distress.pdf)

Andolhe, R., Barbosa, R. L., Oliveira, E. M. de, Costa, A. L. S., Padilha, K. G., Andolhe, R., ... Padilha, K. G. (2015). Stress, coping and burnout among Intensive Care Unit nursing staff: associated factors. *Revista Da Escola de Enfermagem Da USP*, 49, 58–64. doi: <https://doi.org/10.1590/S0080-623420150000700009>

Argent, A. C., Benbenishty, J., & Flaatten, H. (2015). Chronotypes, night shifts and intensive care. *Intensive Care Medicine*, 41(4), 698–700. doi: <https://doi.org/10.1007/s00134-015-3711-7>

Artino Jr, A. R., Durning, S. J., Waechter, D. M., Leary, K. L., & Gilliland, W. R. (2011). Broadening our understanding of clinical quality: From attribution error to situated cognition. *Clinical Pharmacology & Therapeutics*, 91, 167-169. doi: 10.1038/clpt.2011.229

Atkinson, R., & Flint, J. (2001). Accessing hidden and hard-to-reach populations: Snowball research strategies. *Social Research Update*, 33, 1-4. Retrieved from <http://sru.soc.surrey.ac.uk>

Azoulay, E., Chevret, S., Leleu, G., Pochard, F., Barboteu, M., Adrie, C., ... Schlemmer, B. (2000). Half the families of intensive care unit patients experience inadequate communication with physicians. *Critical Care Medicine*, 28(8), 3044–3049.

Azoulay, E., & Herridge, M. (2011). Understanding ICU staff burnout: The show must go on. *American Journal of Respiratory and Critical Care Medicine*, 184(10), 1099–1100. doi: <https://doi.org/10.1164/rccm.201109-1638ED>

Bakker, A. B., Le Blanc, P. M., & Schaufeli, W. B. (2005). Burnout contagion among intensive care nurses. *Journal of Advanced Nursing*, 51(3), 276–287. doi: <https://doi.org/10.1111/j.1365-2648.2005.03494.x>

Bailey, J. (2008). First steps in qualitative transcribing. *Family Practice*, 25(2), 127-131. doi: 10.1093/fampra/cmn003.

Ball, J. E., Murrells, T., Rafferty, A. M., Morrow, E., & Griffiths, P. (2014). “Care left undone” during nursing shifts: associations with workload and perceived quality of care. *BMJ Quality & Safety*, 23(2), 116-125. doi: <https://doi.org/10.1136/bmjqs-2012-001767>

Bakarat, N. Interpersonal skills. *Libyan Journal of Medicine*, 2(3), 152-153. doi: 10.4176/070620

Bastin, A. J., & Firmin, R. (2011). Extracorporeal membrane oxygenation for severe acute respiratory failure in adults: NICE guidance. *Heart*, 97(20), 1701–1703. doi: <https://doi.org/10.1136/heartjnl-2011-300708>

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics*. New York: Oxford University Press.

- Bein, T., Weber-Carstens, S., & Herridge, M. (2015). Extracorporeal life support, ethics, and questions at the bedside: How does the end of the pathway look? *Intensive Care Medicine*, 41(9), 1714–1715. doi: <https://doi.org/10.1007/s00134-015-3696-2>
- Benson, R. A. (1984). *Intensive care units (ICUs): Clinical outcomes, costs, and decisionmaking (Health technology case study 28)*. Washington, DC: Office of Technology Assessment, US Congress.
- Bhaskar, R. A. (1997). *A realist theory of science*. London: Verso.
- Bluhm, R. (2010). The epistemology and ethics of chronic disease research: Further lessons from ECMO. *Theoretical Medicine and Bioethics*, 31(2), 107–122. doi: <https://doi.org/10.1007/s11017-010-9139-8>
- Boling, B., Dennis, D. R., Tribble, T. A., Rajagopalan, N., & Hoopes, C. W. (2016). Safety of nurse-led ambulation for patients on venovenous extracorporeal membrane oxygenation. *Progress in Transplantation*, 26(2), 112–116. doi: <https://doi.org/10.1177/1526924816640646>
- Bombino, M., Redaelli, S., & Patroniti, N. (2014). Patient care during ECMO. In F. Sangalli, N. Patroniti, & A. Pesenti (Eds.), *ECMO-Extracorporeal Life Support in Adults* (pp. 345–359). Springer Milan. doi: [https://doi.org/10.1007/978-88-470-5427-1\\_30](https://doi.org/10.1007/978-88-470-5427-1_30)

Booth, A., Sutton, A., & Papaioannou, D. (2016). *Systematic approaches to a successful literature review* (2nd ed.). London: SAGE Publications Limited.

Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: <http://dx.doi.org/10.1191/1478088706qp063oa>

Brodie, D., & Bacchetta, M. (2011). Extracorporeal Membrane Oxygenation for ARDS in Adults. *New England Journal Of Medicine*, 365, 1905-1914. doi: 10.1056/NEJMct1103720

Broman, L. M., Holzgraefe, B., Palmér, K., & Frenckner, B. (2015). The Stockholm experience: Interhospital transports on extracorporeal membrane oxygenation. *Critical Care*, 19(1), 278–278. doi: <https://doi.org/10.1186/s13054-015-0994-6>

Bruce, C. R. J., Miller, S. M. M., & Zimmerman, J. L. (2015). A qualitative study exploring moral distress in the ICU team: The importance of unit functionality and intrateam dynamics. *Critical Care Medicine*, 43(4), 823–831. doi: <https://doi.org/10.1097/CCM.0000000000000822>

Brum, R., Rajani, R., Gelandt, E., Morgan, L., Raguseelan, N., Butt, S., ... Broughton, S. (2015). Simulation training for extracorporeal membrane oxygenation. *Annals of Cardiac Anaesthesia*, 18(2), 185–190. doi: <https://doi.org/10.4103/0971-9784.154472>

Bryner, B., Cooley, E., Copenhaver, W., Brierley, K., Teman, N., Landis, D., ...

Bartlett, R. H. (2014). Two decades' experience With interfacility transport on extracorporeal membrane oxygenation. *The Annals of Thoracic Surgery*, 98(4), 1363–1370. doi: <https://doi.org/10.1016/j.athoracsur.2014.06.025>

Bucknall, T., & Thomas, S. (1997). Nurses' reflections on problems associated with decision-making in critical care settings. *Journal of Advanced Nursing*, 25, 229–237.

Burrell, A., Pellegrino, V., Pilcher, D., Bernard, S., & Kennedy, M. (2012).

Retrieval of patients with severe respiratory failure on venovenous extracorporeal membrane oxygenation: An intensivist-led model. *Critical Care*, 16(1), 95-96. doi: <https://doi.org/10.1186/cc10702>

Buxman, K. R. (2000). Humor in critical care: No joke. *AACN Clinical Issues: Advanced Practice in Acute & Critical Care Complementary and Alternative Therapies*, 11(1), 120–127.

Caine, R. M., & Ter-Bagdasarian, L. (2003). Early identification and management of critical incident stress. *Critical Care Nurse*, 23(1), 59–65.

Campbell, T. G. (1994). Changing criteria for the artificial lung: Historic controls on the technology of ECMO. *ASAIO Journal*, 40(2), 109–120.



- Carthey, J., De Leval, M. R., & Reason, J. T. (2001). Institutional resilience in healthcare systems. *Quality and Safety in Health Care*, 10(1), 29-32. doi: <http://dx.doi.org/10.1136/qhc.10.1.29>
- Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. Retrieved from: <https://www.york.ac.uk/crd/SysRev/!SSL/!WebHelp/TITLEPAGE.htm>
- Chen, B., & Chang, Y-M. (2008). CPR with assisted extracorporeal life support. *The Lancet*, 372(9653), 1879. doi: [https://doi.org/10.1016/S0140-6736\(08\)61805-X](https://doi.org/10.1016/S0140-6736(08)61805-X)
- Chen, K.-H., Tsai, F.-C., Tsai, C.-S., Yeh, S.-L., Weng, L.-C., & Yeh, L.-C. (2016). Problems and health needs of adult extracorporeal membrane oxygenation patients following hospital discharge: A qualitative study. *Heart & Lung: The Journal of Acute and Critical Care*, 45(2), 147–153. doi: <https://doi.org/10.1016/j.hrtlng.2015.12.005>
- Chen, Y.-Y., Chen, L., Kao, Y.-H., Chu, T.-S., Huang, T.-S., & Ko, W.-J. (2014). The over-optimistic portrayal of life-supporting treatments in newspapers and on the Internet: a cross-sectional study using extra-corporeal membrane oxygenation as an example. *BMC Medical Ethics*, 15, 59. doi: <https://doi.org/10.1186/1472-6939-15-59>

- Chou, N.-K., Chi, N.-H., Yu, H.-Y., Lin, J.-W., Wang, C.-H., Wang, S.-S., & Chen, Y.-S. (2013). Extracorporeal rescue for early and late graft failure after cardiac transplantation: Short result and long-term followup. *The Scientific World Journal*, 2013, e364236. doi: <https://doi.org/10.1155/2013/364236>
- Cianchi, G., Bonizzoli, M., Pasquini, A., Bonacchi, M., Zagli, G., Ciapetti, M., ... Peris, A. (2011). Ventilatory and ECMO treatment of H1N1-induced severe respiratory failure: Results of an Italian referral ECMO center. *BMC Pulmonary Medicine*, 11(1), 2. doi: <https://doi.org/10.1186/1471-2466-11-2>
- Combes, A., Brodie, D., Bartlett, R., Brochard, L., Brower, R., Conrad, S., ... Vuylsteke, A. (2014). Position paper for the organization of extracorporeal membrane oxygenation programs for acute respiratory failure in adult patients. *American Journal of Respiratory and Critical Care Medicine*, 190(5), 488–496. doi: <https://doi.org/10.1164/rccm.201404-0630CP>
- Coomber, S., Todd, C., Park, G., Baxter, P., Firth-Cozens, J., & Shore, S. (2002). Stress in UK intensive care unit doctors. *British Journal of Anaesthesia*, 89(6), 873–881. doi: <https://doi.org/10.1093/bja/aef273>
- Corley, A., Hammond, N. E., & Fraser, J. F. (2010). The experiences of health care workers employed in an Australian intensive care unit during the H1N1 Influenza pandemic of 2009: A phenomenological study. *International Journal of Nursing Studies*, 47(5), 577–585. doi: <https://doi.org/10.1016/j.ijnurstu.2009.11.015>

Corley, M. C. (2002). Nurse moral distress: A proposed theory and research

agenda. *Nursing Ethics*, 9(6), 636–650. doi:

<https://doi.org/10.1191/09697333002ne557oa>

Cottrell, D., & Kendall, S. M. (2010). Are you ready to move into critical care?:

*Nursing*, 40, 20–21. doi:

<https://doi.org/10.1097/01.NURSE.0000387064.52873.08>

Courtright, K. R., & Kerlin, M. P. (2014). Intensive care unit staffing and quality of

care: challenges in times of an intensivist shortage. *Revista Brasileira de*

*Terapia Intensiva*, 26(3), 205–207. doi: <https://doi.org/10.5935/0103->

507X.20140031

Critical Appraisal Skills Programme. (2017). *CASP qualitative checklist*.

Retrieved from:

[http://media.wix.com/ugd/dded87\\_25658615020e427da194a325e7773d42.pdf](http://media.wix.com/ugd/dded87_25658615020e427da194a325e7773d42.pdf)

Crow, S., Fischer, A. C., & Schears, R. M. (2009). Extracorporeal life support:

Utilization, cost, controversy, and ethics of trying to save lives. *Seminars in*

*Cardiothoracic and Vascular Anesthesia*, 13(3), 183–191. doi:

<https://doi.org/10.1177/1089253209347385>

Curley, M. A. Q., & Meyer, E. C. (2003). Parental experience of highly technical therapy: Survivors and nonsurvivors of extracorporeal membrane oxygenation support. *Pediatric Critical Care Medicine: A Journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*, 4(2), 214–219. doi: <https://doi.org/10.1097/01.PCC.0000043915.79848.8D>

Dalle Ave, A. L., Gardiner, D., & Shaw, D. M. (2016). The ethics of extracorporeal membrane oxygenation in brain-dead potential organ donors. *Transplant International: Official Journal of the European Society for Organ Transplantation*, 29(5), 612–618. doi: <https://doi.org/10.1111/tri.12772>

Dalle Ave, A. L., Shaw, D. M., & Bernat, J. L. (2016). Ethical issues in the use of extracorporeal membrane oxygenation in controlled donation after circulatory determination of death. *American Journal of Transplantation*, 16(8), 2293–2299. doi: <https://doi.org/10.1111/ajt.13792>

Dall’Ora, C., Griffiths, P., Ball, J., Simon, M., & Aiken, L. H. (2015). Association of 12 h shifts and nurses’ job satisfaction, burnout and intention to leave: Findings from a cross-sectional study of 12 European countries. *BMJ Open*, 5(9), e008331. doi: <https://doi.org/10.1136/bmjopen-2015-008331>

Danbury, C. M., Gould, T., Baudouin, S., Berry, A., Bolton, S., Borthwick, M., ...

Steen, S. (2013). Core standards for intensive care units. Faculty of Intensive Care Medicine/The Intensive Care Society. Retrieved from [https://www.ficm.ac.uk/sites/default/files/Core%20Standards%20for%20ICUs%20Ed.1%20\(2013\).pdf](https://www.ficm.ac.uk/sites/default/files/Core%20Standards%20for%20ICUs%20Ed.1%20(2013).pdf)

Dannenfeldt, G. (1982). The psychological aspects of intensive care units.

*Curationis*, 5(3). doi: <https://doi.org/10.4102/curationis.v5i3.425>

DePasquale, E. C., Cheng, R. K., Baas, A., Cadeiras, M., Cruz, D., Kwon, M., ...

Deng, M. C. (2013). Outcomes of heart transplant (HT) recipients bridged with ECMO. *The Journal of Heart and Lung Transplantation*, 32(4), S141. doi: <https://doi.org/10.1016/j.healun.2013.01.318>

Dodek, P. M., Wong, H., Norena, M., Ayas, N., Reynolds, S. C., Keenan, S. P.,

... Alden, L. (2016). Moral distress in intensive care unit professionals is associated with profession, age, and years of experience. *Journal of Critical Care*, 31(1), 178–182. doi: <https://doi.org/10.1016/j.jcrc.2015.10.011>

Donnelly, S. M., & Psirides, A. (2015). Relatives' and staff's experience of patients dying in ICU. *QJM*, 108(12), 935–942. doi:

<https://doi.org/10.1093/qjmed/hcv059>

- Efstathiou, N., & Walker, W. (2014). Intensive care nurses' experiences of providing end-of-life care after treatment withdrawal: a qualitative study. *Journal of Clinical Nursing*, 23(21–22), 3188–3196.
- Eisendrath, S. J., & Dunkel, J. (1979). Psychological issues in intensive care unit staff. *Heart & Lung: The Journal of Critical Care*, 8(4), 751–758.
- Ellinger, F., & Wydro, G. (2009). Critical transport issues. Interfacility transportation of a patient on ECMO. *EMS Magazine*, 38(10), 71–73.
- Embriaco, N., Azoulay, E., Barrau, K., Kentish, N., Pochard, F., Loundou, A., & Papazian, L. (2007). High level of burnout in intensivists. *American Journal of Respiratory and Critical Care Medicine*, 175(7), 686–692. doi: <https://doi.org/10.1164/rccm.200608-1184OC>
- Embriaco, N., Hraiech, S., Azoulay, E., Baumstarck-Barrau, K., Forel, J.-M., Kentish-Barnes, N., ... Papazian, L. (2012). Symptoms of depression in ICU physicians. *Annals of Intensive Care*, 2, 34. doi: <https://doi.org/10.1186/2110-5820-2-34>
- Epps, S., & Nowak, T. A. (1998). Parental perception of neonatal extracorporeal membrane oxygenation. *Children's Health Care*, 27(4), 215–230. doi: [https://doi.org/10.1207/s15326888chc2704\\_1](https://doi.org/10.1207/s15326888chc2704_1)

Epstein, E. G., & Delgado, S. (2010). Understanding and addressing moral distress. *The Online Journal of Issues in Nursing*, 15(3). doi: 10.3912/OJIN.Vol15No03Man01

Ericsson, A., Frenckner, B., & Broman, L. M. (2017). Adverse events during inter-hospital transports on extracorporeal membrane oxygenation. *Prehospital Emergency Care*, 0(0), 1–8. doi: <https://doi.org/10.1080/10903127.2017.1282561>

Fan, E., & Pham, T. (2014). Extracorporeal membrane oxygenation for severe acute respiratory failure: Yes we can! (But should we?). *American Journal of Respiratory & Critical Care Medicine*, 189(11), 1293–1295. doi: <https://doi.org/10.1164/rccm.201404-0711ED>

Flannery, L., Ramjan, L. M., & Peters, K. (2016). End-of-life decisions in the intensive care unit (ICU) – Exploring the experiences of ICU nurses and doctors – a critical literature review. *Australian Critical Care*, 29(2), 97–103. doi: <https://doi.org/10.1016/j.aucc.2015.07.004>

Frosh, S., & Saville-Young, L. (2008). Psychoanalytic approaches to qualitative psychology. In C. Willig & W. Stainton Rogers (Eds.), *The sage handbook of qualitative research in psychology* (pp. 109-126). London, England: Sage.

Garrouste-Orgeas, M., Perrin, M., Soufir, L., Vesin, A., Blot, F., Maxime, V., ...

Timsit, J.-F. (2015). The latroref study: Medical errors are associated with symptoms of depression in ICU staff but not burnout or safety culture.

*Intensive Care Medicine*, 41(2), 273–284. doi:

<https://doi.org/10.1007/s00134-014-3601-4>

Gattinoni, L., Carlesso, E., & Langer, T. (2011). Clinical review: Extracorporeal membrane oxygenation. *Critical Care*, 15(6), 243. doi:

<https://doi.org/10.1186/cc10490>

Gauntlett, R., & Laws, D. (2008). Communication skills in critical care. *Continuing Education in Anaesthesia Critical Care & Pain*, 8(4), 121–124. doi:

<https://doi.org/10.1093/bjaceaccp/mkn024>

Gawande, A. (2015). *Being mortal: Illness, medicine and what matters in the end*. London: Profile Books LTD.

Gay S. E., Ankney N, Cochran J. B, & Highland K. B. (2005). Critical care challenges in the adult ECMO patient. *Dimensions of Critical Care Nursing*, 24(4), 157–164.

Gibbs, G. (1988). *Learning by doing: A guide to teaching and learning methods*. Oxford: Oxford Polytechnic.



- Gilbert, P. (2009). Introducing compassion-focused therapy. *Advances in psychiatric treatment*, 15(3), 199-208. doi: 10.1192/apt.bp.107.005264
- Gilbert, P. (2010). An introduction to compassion focused therapy in Cognitive Behaviour Therapy. *International Journal of Cognitive Therapy*, 3(2), 97-112. doi: 10.1521/ijct.2010.3.2.97
- Goodfellow, A., Varnam, R., Rees, D., & Shelly, M. P. (1997). Staff stress on the intensive care unit: A comparison of doctors and nurses. *Anaesthesia*, 52(11), 1037–1041. doi: <https://doi.org/10.1111/j.1365-2044.1997.213-az0348.x>
- Gulack, B. C., Hirji, S. A., & Hartwig, M. G. (2014). Bridge to lung transplantation and rescue post-transplant: the expanding role of extracorporeal membrane oxygenation. *Journal of Thoracic Disease*, 6(8), 1070–1079. doi: <https://doi.org/10.3978/j.issn.2072-1439.2014.06.04>
- Guntupalli, K. K., Wachtel, S., Mallampalli, A., & Surani, S. (2014). Burnout in the intensive care unit professionals. *Indian Journal of Critical Care Medicine : Peer-Reviewed, Official Publication of Indian Society of Critical Care Medicine*, 18(3), 139–143. doi: <https://doi.org/10.4103/0972-5229.128703>
- Gutierrez KM. (2005). Critical care nurses' perceptions of and responses to moral distress. *Dimensions of Critical Care Nursing*, 24(5), 229–241.

Haghenbeck, K. T. (2005). Critical care nurses' experiences when technology malfunctions. *The Journal of the New York State Nurses' Association*, 36(1), 13–19.

Halpern, J. (2003). What is clinical empathy? *Journal of General Internal Medicine*, 18(8), 670-674. doi: 10.1046/j.1525-1497.2003.21017.x

Happ, M. B., Garrett, K., Thomas, D. D., Tate, J., George, E., Houze, M., ... Sereika, S. (2011). Nurse-patient communication interactions in the intensive care unit. *American Journal of Critical Care : An Official Publication, American Association of Critical-Care Nurses*, 20(2), e28–e40. doi: <https://doi.org/10.4037/ajcc2011433>

Harris, S. (2002). Nurses' views on withdrawing ECMO: A grounded theory study. *Nursing in Critical Care*, 7(3), 144–151.

Harris-Fox, S. (2012). The experience of being an “extracorporeal membrane oxygenation” relative within the CESAR trial. *Nursing in Critical Care*, 17(1), 9–18. doi: <https://doi.org/10.1111/j.1478-5153.2011.00452.x>

Hastings, S. L., Pellegrino, V. A., Prevolos, A., & Salamonsen, R. F. (2008). Survey of adult extracorporeal membrane oxygenation (ECMO) practice and attitudes among Australian and New Zealand intensivists. *Critical Care and Resuscitation: Journal of the Australasian Academy of Critical Care Medicine*, 10(1), 46.

Hijeh, M. (2017). ECMO nurse specialist: Qatar experience. *Qatar Medical Journal*, 1(1). doi:

<https://doi.org/http://dx.doi.org/10.5339/qmj.2017.swacelso.55>

Honey, M., & Wang, W. Y. (2012). New Zealand nurses perceptions of caring for patients with influenza A (H1N1). *Nursing in Critical Care*, 18(2), 63–69. doi: <https://doi.org/10.1111/j.1478-5153.2012.00520.x>

Jameton, A. (1984). *Nursing practice: The ethical issues*. Englewood Cliffs, N.J.: Prentice-Hall.

Jaouni, H. (2017). Application of ethical principles to VV-ECMO patients in Qatar. *Qatar Medical Journal*, (1), 1–2. doi: <https://doi.org/http://dx.doi.org/10.5339/qmj.2017.swacelso.48>

Jenkins, B. B., & Warren, N. A. (2012). Concept analysis: Compassion fatigue and effects upon critical care nurses. *Critical Care Nursing Quarterly*, 35(4), 388–395. doi: <https://doi.org/10.1097/CNQ.0b013e318268fe09>

Joffe, H., & Yardley, L. (2004). Content and thematic analysis. In Marks, D.F. and Yardley, L. (Eds.), *Research methods in clinical and health psychology* (pp. 56-68). London, England: Sage.

Jones, C., Hommers, C., Burns, B., & Forrest, P. (2010). ECMO retrieval in NSW and beyond. *Current Anaesthesia & Critical Care*, 21(5–6), 282–286. doi: <https://doi.org/10.1016/j.cacc.2010.07.004>

Kagee, A. (2002). Concerns about the effectiveness of critical incident stress debriefing in ameliorating stress reactions. *Critical Care*, 6(1), 88. doi: <https://doi.org/10.1186/cc1459>

Kaloostian, P. E. (2013). *The young neurosurgeon: Lessons from my patients*. Albuquerque: University of New Mexico Press.

Kälvemark, S., Höglund, A. T., Hansson, M. G., Westerholm, P., & Arnetz, B. (2004). Living with conflicts-ethical dilemmas and moral distress in the health care system. *Social Science & Medicine (1982)*, 58(6), 1075–1084. doi: [https://doi.org/10.1016/S0277-9536\(03\)00279-X](https://doi.org/10.1016/S0277-9536(03)00279-X)

Karasek, R. A. (1979). Job demands, job decision latitude, and mental strain: Implications for job redesign. *Administrative Science Quarterly*, 24(2), 285–308. doi: <https://doi.org/10.2307/2392498>

Klinedinst, R., O'Connor, N., & Farabelli, J. (2017). Walking across the bridge to nowhere: The role of palliative care in the support of patients on ECMO. *Journal of Pain and Symptom Management*, 53(2), 350. doi: <https://doi.org/10.1016/j.jpainsymman.2016.12.096>

- Kneebone, R. L. (2016) Performing surgery: Commonalities with performers outside medicine. *Frontiers in Psychology*, 7(1233), 1-17. doi: 10.3389/fpsyg.2016.01233
- Langer, T., Santini, A., Bottino, N., Crotti, S., Batchinsky, A. I., Pesenti, A., & Gattinoni, L. (2016). "Awake" extracorporeal membrane oxygenation (ECMO): Pathophysiology, technical considerations, and clinical pioneering. *Critical Care*, 20, 150. doi: <https://doi.org/10.1186/s13054-016-1329-y>
- Lenart, S. B. M., Bauer, C. G. B., Brighton, D. D. B., Johnson, J. J. M., & Stringer, T. M. B. (1998). Grief support for nurses in the ICU. *Journal for Nurses in Staff Development - JNSD*, 14(6), 293–296.
- Lindahl, B., & Norberg, A. (2002). Clinical group supervision in an intensive care unit: a space for relief, and for sharing emotions and experiences of care: Clinical group supervision. *Journal of Clinical Nursing*, 11(6), 809–818. doi: <https://doi.org/10.1046/j.1365-2702.2002.00652.x>
- Lindstrom, S. J., Pellegrino, V. A., & Butt, W. W. (2009). Extracorporeal membrane oxygenation. *Medical Journal of Australia*, 191(3). Retrieved from <https://www.mja.com.au/journal/2009/191/3/extracorporeal-membrane-oxygenation>

Lown, B. A., & Manning, C. F. (2010). The Schwartz center rounds: Evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support. *Academic Medicine: Journal of the Association of American Medical Colleges*, 85(6), 1073–1081. doi: <https://doi.org/10.1097/ACM.0b013e3181dbf741>

Loxley, A. (1997). *Collaboration in health and welfare: Working with difference*. London: Jessica Kingsley Publishers.

Makdisi, G., & Wang, I. -we. (2015). Extra corporeal membrane oxygenation (ECMO) review of a lifesaving technology. *Journal of Thoracic Disease*, 7(7), 166–176.

Maltese, F., Adda, M., Bablon, A., Hraeich, S., Guervilly, C., Lehingue, S., ... Papazian, L. (2016). Night shift decreases cognitive performance of ICU physicians. *Intensive Care Medicine*, 42(3), 393–400. doi: <https://doi.org/10.1007/s00134-015-4115-4>

Marsella, A. J. (2013). All psychologies are indigenous psychologies: Reflections on psychology in a global era. *Psychology International*, 24(4), 5-7. Retrieved from: <http://www.apa.org/international/pi/2013/12/issue.pdf>

Martinez, G., & Vuylsteke, A. (2012). Extracorporeal membrane oxygenation in adults. *Continuing Education in Anaesthesia Critical Care & Pain*, 12(2), 57–61. doi: <https://doi.org/10.1093/bjaceaccp/mkr056>

Martins, J. T., & Robazzi, M. L. do C. C. (2009). Nurses' work in intensive care units: Feelings of suffering. *Revista Latino-Americana de Enfermagem*, 17(1), 52–58. doi: <https://doi.org/10.1590/S0104-11692009000100009>

Maxwell, J. A. (2012). *A realist approach for qualitative research*. London: Sage.

McHenry, L. (1981). Situational anxiety levels and the intensive care unit staff nurse. *Issues in Mental Health Nursing*, 3(4), 341–351. doi: <https://doi.org/10.3109/01612848109141034>

McHugh, M. L. (2012). Interrater reliability: The Kappa statistic. *Biochemica Medica*, 22(3), 276-282. doi: <http://dx.doi.org/10.11613/BM.2012.031>

Mealer, M. L., Shelton, A., Berg, B., Rothbaum, B., & Moss, M. (2007). Increased prevalence of post-traumatic stress disorder symptoms in critical care nurses. *American Journal of Respiratory and Critical Care Medicine*, 175(7), 693–697. doi: <https://doi.org/10.1164/rccm.200606-735OC>

Meltzer, E. C., Ivascu, N. S., Acres, C. A., Stark, M., Kirkpatrick, J. N., Subroto, P., Sedrakyan, A., ... Fins, J. J. (2014). Extracorporeal membrane oxygenation in adults: A brief review and ethical considerations for nonspecialist health providers and hospitalists. *Journal of Hospital Medicine*, 9(12), 808-813. doi: 10.1002/jhm.2262

Meltzer, E. C., Ivascu, N. S., & Fins, J. J. (2014). DNR and ECMO: A paradox worth exploring. *Journal of Clinical Ethics*, 25(1), 13-19.

Meltzer, E. C., Ivascu, N. S., Stark, M., Orfanos, A. V., Acres, C. A., Christos, P. J., Manigione, T., ... Fins, J. J. (2016). A survey of physicians' attitudes toward decision-making authority for initiating and withdrawing VA-ECMO: Results and ethical implications for shared decision making. *Journal of Clinical Ethics*, 27(4), 281-289.

Menzies-Lyth, I. (1988). *Containing anxiety in institutions: Selected essays* (Vol. 1). London: Free Association Books.

Miranda, D. R., Abkenari, L. D., Nieman, K., Dijkshoorn, M., Duckers, E., & Gommers, D. (2012). Myocardial infarction due to malposition of ECMO cannula. *Intensive Care Medicine*, 38(7), 1233–1234. doi: <https://doi.org/10.1007/s00134-012-2583-3>



- Modra, L., & Hilton, A. (2013). Ethical issues in resuscitation and intensive care medicine. *Anaesthesia & Intensive Care Medicine*, 14(1), 8–10. doi: <https://doi.org/10.1016/j.mpaic.2012.11.005>
- Mol, M. M. C. van, Kompanje, E. J. O., Benoit, D. D., Bakker, J., & Nijkamp, M. D. (2015). The prevalence of compassion fatigue and burnout among healthcare professionals in intensive care units: A systematic review. *PLOS ONE*, 10(8), e0136955. doi: <https://doi.org/10.1371/journal.pone.0136955>
- Mongero, L., Beck, J., & Charette, K. (2013). Managing the extracorporeal membrane oxygenation (ECMO) circuit integrity and safety utilizing the perfusionist as the “ECMO Specialist.” *Perfusion*, 28(6), 552–554. doi: <https://doi.org/10.1177/0267659113497230>
- Morris, A. H. (1993). Cost-benefit considerations in managing oxygenation failure. *Respiratory Care*, 38(7), 829-838.
- Mosier, J. M., Kelsey, M., Raz, Y., Gunnerson, K. J., Meyer, R., Hypes, C. D., ... Spaite, D. W. (2015). Extracorporeal membrane oxygenation (ECMO) for critically ill adults in the emergency department: History, current applications, and future directions. *Critical Care*, 19, 431. doi: <https://doi.org/10.1186/s13054-015-1155-7>

Moyen, E., Camiré, E., & Stelfox, H. T. (2008). Clinical review: Medication errors in critical care. *Critical Care*, 12(2), 208. doi: <https://doi.org/10.1186/cc6813>

Muralidharan, R., Mateen, F. J., Shinohara, R. T., Schears, G. J., & Wijdicks, E. F. M. (2011). The challenges with brain death determination in adult patients on extracorporeal membrane oxygenation. *Neurocritical Care*, 14(3), 423–426. doi: <https://doi.org/10.1007/s12028-011-9516-9>

Myhren, H., Ekeberg, Ø., & Stokland, O. (2013). Job satisfaction and burnout among intensive care unit nurses and physicians. *Critical Care Research and Practice*, (2013),1-6. doi: <https://doi.org/10.1155/2013/786176>

Nelson, J. (2016). Using conceptual depth criteria: Addressing the challenge of reaching saturation in qualitative research. *Qualitative Research*, 16(6), 1-17. doi: <https://doi.org/10.1177/1468794116679873>

Nelson, R. M. (1997). Ethics in the intensive care unit: Creating an ethical environment. *Critical Care Clinics*, 13(3), 691–701. doi: [https://doi.org/10.1016/S0749-0704\(05\)70335-3](https://doi.org/10.1016/S0749-0704(05)70335-3)

Noble, H., & Smith, J. (2015). Issues in reliability and validity in qualitative research. *Evidence Based Nursing*, 18(1), 34-35. doi: 10.1136/eb-2015-102054

Norris, N. (1997). Error, bias and validity in qualitative research. *Educational Action Research*, 5(1), 172-176. doi:

<http://dx.doi.org/10.1080/09650799700200020>

Obholzer, A., & Zagier Roberts, V. (Eds.) (2003). *The unconscious at work: Individual and organizational stress in the human services*. London: Routledge.

O'Brien, S., & Pellegrino, V. (2008). Expanding the scope of nursing practice in caring for patients supported on extracorporeal membrane oxygenation (ECMO). *Australian Critical Care*, 21(1), 59. doi: <https://doi.org/10.1016/j.aucc.2007.12.019>

Özgencil, E., Ünal, N., Oral, M., Okyavuz, Ü., Alanoglu, Z., & Tulunay, M. (2004). Depression and burnout syndrome in intensive care unit nurses. *Critical Care*, 8(Suppl 1), P340. doi: <https://doi.org/10.1186/cc2807>

Padesky, C. A. (1996). Developing cognitive therapist competency: training and supervision models. In P. M. Salkovskis, *Frontiers of Cognitive Therapy* (pp. 266–292). New York: Guilford Press.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental health*, 42(5), 533-544. doi: 10.1007/s10488-013-0528-y

- Papadimos, T. J., Maldonado, Y., Tripathi, R. S., Kothari, D. S., & Rosenberg, A. L. (2011). An overview of end-of-life issues in the intensive care unit. *International Journal of Critical Illness and Injury Science*, 1(2), 138–146. doi: <https://doi.org/10.4103/2229-5151.84801>
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Beverley Hills, CA: Sage.
- Peek, G. J., Mugford, M., Tiruvoipati, R., Wilson, A., Allen, E., Thalanany, M. M., ... Elbourne, D. (2009). Efficacy and economic assessment of conventional ventilatory support versus extracorporeal membrane oxygenation for severe adult respiratory failure (CESAR): A multicentre randomised controlled trial. *The Lancet*, 374(9698), 1351–1363. doi: [https://doi.org/10.1016/S0140-6736\(09\)61069-2](https://doi.org/10.1016/S0140-6736(09)61069-2)
- Peetz, A. B., Sadovnikoff, N., & O'Connor, M. F. (2015). Is informed consent for extracorporeal life support even possible? *AMA Journal of Ethics*, 17(3), 236. doi: <https://doi.org/10.1001/journalofethics.2015.17.3.stas1-1503>
- Poncet, M. C., Toullic, P., Papazian, L., Kentish-Barnes, N., Timsit, J.-F., Pochard, F., ... Azoulay, É. (2007). Burnout syndrome in critical care nursing staff. *American Journal of Respiratory and Critical Care Medicine*, 175(7), 698–704. doi: <https://doi.org/10.1164/rccm.200606-806OC>

Puri, N., Puri, V., & Dellinger, R. P. (2009). History of technology in the intensive care unit. *Critical Care Clinics*, 25(1), 185–200, 9. doi:

<https://doi.org/10.1016/j.ccc.2008.12.002>

Quill, T. E., & Townsend, P. (1991). Bad news: Delivery, dialogue, and dilemmas. *Archives of Internal Medicine*, 151, 463-468.

Ramanathan, K., Cove, M. E., Caleb, M. G., Teoh, K. L. K., & Maclaren, G.

(2015). Ethical dilemmas of adult ECMO: Emerging conceptual challenges. *Journal of Cardiothoracic and Vascular Anesthesia*, 29(1), 229–233. doi: <https://doi.org/10.1053/j.jvca.2014.07.015>

Raza, T. (2017). 300 days plus on ECMO - Lessons learned. *Qatar Medical Journal*, 1(1). <https://doi.org/10.5339/qmj.2017.swacelso.49>

Regan, A. (2014, November 20). Psychology and palliative care services working together-on cultivating multi-disciplinary meetings and ensuring compassion in care [Web log comment]. Retrieved from <http://blogs.bmj.com/spcare/2014/11/20/psychology-and-palliative-care-services-working-together-on-cultivating-multi-disciplinary-meetings-and-ensuring-compassion-in-care/>

Regan, A., Howard, R. A., & Oyebode, J. R. (2009). Emotional exhaustion and defense mechanisms in intensive therapy unit nurses. *Journal of Nervous and Mental Disease*, 197(5), 330-336. doi: 10.1097/NMD.0b013e3181a20807

Reznik, O. I. (2006). *The secrets of medical decision making: How to avoid becoming a victim of the health care machine*. Ann Arbor, MI: Loving Healing Press.

Richardson, A., Turnock, C., Harris, L., Finley, A., & Carson, S. (2007). A study examining the impact of 12-hour shifts on critical care staff. *Journal of Nursing Management*, 15(8), 838–846. doi: <https://doi.org/10.1111/j.1365-2934.2007.00767.x>

Robinson, J. S. (1966). The design and function of an intensive care unit. *British Journal of Anaesthesia*, 38(2), 132–142. doi: <https://doi.org/10.1093/bja/38.2.132>

Rotter, J. B. (1966). Generalised expectancies for internal versus external control of reinforcement. *Psychological Monographs: General and Applied*, 80(1), 1-28.

Sandelowski, M. (1994). Focus on qualitative methods: Notes on transcription. *Research in Nursing and Health*, 17(4), 311-314. doi: 10.1002/nur.4770170410

Schmidt, M., Bailey, M., Sheldrake, J., Hodgson, C., Aubron, C., Rycus, P. T., ...

Pilcher, D. (2014). Predicting survival after extracorporeal membrane oxygenation for severe acute respiratory failure. The Respiratory Extracorporeal Membrane Oxygenation Survival Prediction (RESP) score. *American Journal of Respiratory & Critical Care Medicine*, 189(11), 1374–1382. doi: <https://doi.org/10.1164/rccm.201311-2023OC>

Schmidt, M., Bréchet, N., & Combes, A. (2016). Ten situations in which ECMO is unlikely to be successful. *Intensive Care Medicine*, 42(5), 750–752. doi: <https://doi.org/10.1007/s00134-015-4013-9>

Schmidt, M., Zogheib, E., Rozé, H., Repesse, X., Lebreton, G., Luyt, C.-E., ...

Combes, A. (2013). The PRESERVE mortality risk score and analysis of long-term outcomes after extracorporeal membrane oxygenation for severe acute respiratory distress syndrome. *Intensive Care Medicine*, 39(10), 1704–1713. doi: <https://doi.org/10.1007/s00134-013-3037-2>

Schwalbe, M. & Wolkowicz, M. (2001) The masculine self as a problem and resource in interview studies of men. *Men and Masculinities*, 4(1), 90-103. doi: 10.1177/1097184X01004001005

Senussi, M. H. (2014). Respite from the RESP Score. *American Journal of Respiratory and Critical Care Medicine*, 190(8), 962–963. doi: <https://doi.org/10.1164/rccm.201407-1274LE>

- Shapiro, J. (2012). The feeling physician: Educating the emotions in medical training. *European Journal for Person Centered Healthcare*, 1(2), 310-316.
- Shorter, M., & Stayt, L. C. (2010). Critical care nurses' experiences of grief in an adult intensive care unit. *Journal of Advanced Nursing*, 66(1), 159–167. doi: <https://doi.org/10.1111/j.1365-2648.2009.05191.x>
- Silva, R. C. da, & Ferreira, M. de A. (2011). Technology in intensive care and its effects on nurses' actions. *Revista Da Escola de Enfermagem Da USP*, 45(6), 1403–1411. doi: <https://doi.org/10.1590/S0080-62342011000600018>
- Smith, J. (2016). Sailing through social LA GGRRAACCEESS: Tool for deconstructing and facilitating reflective and reflexive practice. *Reflective Practice*, 17(5), 570-582. doi: <http://dx.doi.org/10.1080/14623943.2016.1184634>
- Söderström I, Benzein E, & Saveman B. (2003). Nurses' experiences of interactions with family members in intensive care units. *Scandinavian Journal of Caring Sciences*, 17(2), 185–192.
- Starck, C. T., Hasenclever, P., Falk, V., & Wilhelm, M. J. (2013). Interhospital transfer of seriously sick ARDS patients using veno-venous Extracorporeal Membrane Oxygenation (ECMO): Concept of an ECMO transport team. *International Journal of Critical Illness and Injury Science*, 3(1), 46-50.



- Stuckey, H. (2014). Methodological issues in social health and diabetes research. *Journal of Social, Health and Diabetes*, 2(1), 6-8. doi: 10.4103/2321-0656.120254
- Stulak, J. M., Dearani, J. A., Burkhart, H. M., Barnes, R. D., Scott, P. D., & Schears, G. J. (2009). ECMO Cannulation Controversies and Complications. *Seminars in Cardiothoracic and Vascular Anesthesia*, 13(3), 176–182. doi: <https://doi.org/10.1177/1089253209347943>
- Teixeira, C., Ribeiro, O., Fonseca, A. M., & Carvalho, A. S. (2013). Burnout in intensive care units - a consideration of the possible prevalence and frequency of new risk factors: A descriptive correlational multicentre study. *BMC Anesthesiology*, 13(1). doi: <https://doi.org/10.1186/1471-2253-13-38>
- The Royal College of Psychiatrists. (2015). Compassion in care: ten things you can do to make a difference. The Royal College of Psychiatrists. Retrieved from [http://www.rcpsych.ac.uk/pdf/FR-GAP-02\\_Compassionate-care.pdf](http://www.rcpsych.ac.uk/pdf/FR-GAP-02_Compassionate-care.pdf)
- The Society of Clinical Perfusion Scientists of Great Britain and Ireland. (2008). The Clinical Perfusion Scientist. The Society of Clinical Perfusion Scientists of Great Britain and Ireland. Retrieved from [https://www.scps.org.uk/index.php?option=com\\_content&task=view&id=55&Itemid=58](https://www.scps.org.uk/index.php?option=com_content&task=view&id=55&Itemid=58)

Thiagarajan, R. R., & Barrett, C. S. (2011). ECMO - Indications and outcomes.

Society of Critical Care Medicine. Retrieved from

<http://www.sccm.org/Communications/Critical->

[Connections/Archives/Pages/ECMO---Indications-and-Outcomes.aspx](http://www.sccm.org/Communications/Critical-Connections/Archives/Pages/ECMO---Indications-and-Outcomes.aspx)

Timimi, S. (2014). No more psychiatric labels: Why formal psychiatric diagnostic systems should be abolished. *International Journal of Clinical and Health Psychology*, 14(3), 208-215. doi: <https://doi.org/10.1016/j.ijchp.2014.03.004>

Tramm, R., Ilic, D., Davies, A., Pellegrino, V., Romero, L., & Hodgson, C. (2015).

Extracorporeal membrane oxygenation for critically ill adults in ICU – A nurse-led multidisciplinary Cochrane Collaboration systematic review.

*Australian Critical Care*, 28(1), 48–49. doi:

<https://doi.org/10.1016/j.aucc.2014.10.030>

Tramm, R., Ilic, D., Hodgson, C., Murphy, K., Sheldrake, J., & Pellegrino, V.

(2016). Experience and needs of family members of patients treated with extracorporeal membrane oxygenation (ECMO). *Journal of Clinical*

*Nursing*. doi: <https://doi.org/10.1111/jocn.13566>

Tramm, R., Ilic, D., Murphy, K., Sheldrake, J., Pellegrino, V., & Hodgson, C.

(2016). A qualitative exploration of acute care and psychological distress experiences of ECMO survivors. *Heart & Lung: The Journal of Acute and Critical Care*, 45(3), 220–226. doi:

<https://doi.org/10.1016/j.hrtlng.2016.01.010>

Truog, R. D. (1992). Randomized controlled trials: Lessons from ECMO. *Clinical Research*, 40(3), 519–527.

Tunlind, A., Granström, J., & Engström, Å. (2015). Nursing care in a high-technological environment: Experiences of critical care nurses. *Intensive and Critical Care Nursing*, 31(2), 116–123. doi: <https://doi.org/10.1016/j.iccn.2014.07.005>

Turner, D. A., & Cheifetz, I. M. (2013). Extracorporeal membrane oxygenation for adult respiratory failure discussion. *Respiratory Care*, 58(6), 1038–1052. doi: <https://doi.org/10.4187/respcare.02255>

Valentin, A., & Ferdinande, P. (2011). Recommendations on basic requirements for intensive care units: Structural and organizational aspects. *Intensive Care Medicine*, 37(10), 1575. doi: <https://doi.org/10.1007/s00134-011-2300-7>

Vargas, D. de, & Dias, A. P. V. (2011). Depression prevalence in intensive care unit nursing workers: A study at hospitals in a northwestern city of São Paulo State. *Revista Latino-Americana de Enfermagem*, 19(5), 1114–1121. doi: <https://doi.org/10.1590/S0104-11692011000500008>

Vincent, J. L. (2013). Critical care - where have we been and where are we going? *Critical Care*, 17(1), 1–6. doi: <https://doi.org/10.1186/cc11500>

Wåhlin, I., Ek, A.-C., & Idvall, E. (2010). Staff empowerment in intensive care: Nurses' and physicians' lived experiences. *Intensive and Critical Care Nursing*, 26(5), 262–269. doi: <https://doi.org/10.1016/j.iccn.2010.06.005>

Walsh, D. & Evans, K. (2014). Critical realism: An important theoretical perspective for midwifery research. *Midwifery*, 30(1), 1-6. doi: <http://dx.doi.org/10.1016/j.midw.2013.09.002>

Wang, W. Y. Q., & Honey, M. (2012). Acute respiratory failure brings challenges to ECMO nurses in flu pandemic. *Nursing New Zealand*, 18(9), 26–27.

Wellman, J., Lepori, F., Szlachcic, R. (2016). Exploring the utility of a pilot tree of life group in an inpatient setting. *Journal of Mental Health Training, Education and Practice*, 11(3), 172-181. doi: <http://dx.doi.org/10.1108/JMHTEP-01-2016-0007>

Whitehead, P. B., Herbertson, R. K., Hamric, A. B., Epstein, E. G., & Fisher, J. M. (2015). Moral distress among healthcare professionals: Report of an institution-wide survey. *Journal of Nursing Scholarship: An Official Publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau*, 47(2), 117–125. doi: <https://doi.org/10.1111/jnu.12115>

Whiting L.S. (2008) Semi-structured interviews: guidance for novice researchers. *Nursing Standard*, 22(23), 35-40. doi: <http://dx.doi.org/10.7748/ns2008.02.22.23.35.c6420>

Whyte W. F. (1984). *Learning from the field: A guide from experience*. London, Sage.

Wiegand, D. L., & Funk, M. (2012). Consequences of clinical situations that cause critical care nurses to experience moral distress. *Nursing Ethics*, 19(4), 479–487. doi: <https://doi.org/10.1177/0969733011429342>

Williams, S. B. & Dahnke, M. D. (2016). Clarification and mitigation of ethical problems surrounding withdrawal of extracorporeal membrane oxygenation. *Critical Care Nurse*, 3(5), 56-65. doi: <http://dx.doi.org/10.4037/ccn2016504>

Willig, C. (2012). Perspectives on the epistemological bases for qualitative research. In H. Cooper, P. Camic, D. L. Long, A. T. Panter, D. Rindskopf & K. J. Sher (Eds.), *APA handbook of research methods in psychology* (Vol 1.): *Foundations planning, measures and psychometrics* (pp. 5-21). Washington, DC: American Psychological Association.

Yardley, L. (2000) Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215-228, doi: 10.1080/08870440008400302

Zangrillo, A., Landoni, G., Biondi-Zoccai, G., Greco, M., Greco, T., Frati, G., ...

Pappakardo, F. (2013). A meta-analysis of complications and mortality of extracorporeal membrane oxygenation. *Critical Care and Resuscitation: Journal of the Australasian Academy of Critical Care Medicine*, 15(3), 172–178.

Zhang, X.-C., Huang, D.-S., Guan, P., Gu, C.-M., Hu, L.-H., Li, H.-F., ... Zhen, L.-

Y. (2014). Job burnout among critical care nurses from 14 adult intensive care units in northeastern China: A cross-sectional survey. *BMJ Open*, 4(6), e004813. doi: <https://doi.org/10.1136/bmjopen-2014-004813>

## 6. APPENDICES

### 6.1. Appendix A – Systematic Literature Search Terms

Table iv.					
<i>Systematic Literature Search Findings: Number of Articles Identified in Thesaurus and Free Text Boolean Searches within Different Academic Databases</i>					
<u>Database</u>	<u>Thesaurus terms used</u>	<u>Free text search: boolean terms/phrases</u>	<u>Number of new relevant articles found</u>	<u>Total articles</u>	<u>Date of search</u>
CINAHL	<b>Key word:</b> Extracorporeal Membrane Oxygenation <b>Subheadings:</b> Adverse Effects, Contraindications, Economics, Education, Equipment and Supplies, Ethical Issues, Legislation and Jurisprudence, Nursing, Psychosocial factors, Standards		25	25	20/03/2017
		Extracorporeal membrane oxygenation AND Staff AND Experiences	2	27	20/03/2017
		ECMO AND Staff AND Experiences	0	27	20/03/2017

Extracorporeal Membrane Oxygenation AND Nurse AND Experiences	0	27	20/03/201 7
ECMO AND Nurse AND Experiences	0	27	20/03/201 7
Extracorporeal Membrane Oxygenation AND Doctor AND Experiences	0	27	20/03/201 7
ECMO AND Doctor AND Experiences	0	27	20/03/201 7
Extracorporeal Membrane Oxygenation AND Physician AND Experiences	1	28	20/03/201 7
ECMO AND Physician AND Experiences	0	28	20/03/201 7
Extracorporeal membrane oxygenation AND Psychological	0	28	20/03/201 7
ECMO AND Psychological	0	28	20/03/201 7
Extracorporeal membrane oxygenation AND Stress	0	28	20/03/201 7
ECMO AND Stress	0	28	20/03/201 7
Extracorporeal membrane oxygenation AND Burnout	0	28	20/03/201 7
ECMO AND Burnout	0	28	20/03/201 7



Extracorporeal membrane oxygenation AND Coping	0	28	20/03/201 7
ECMO AND Coping	0	28	20/03/201 7
Extracorporeal membrane oxygenation AND Growth	0	28	20/03/201 7
ECMO AND Growth	0	28	20/03/201 7
Extracorporeal membrane oxygenation AND Resilience	0	28	20/03/201 7
ECMO AND Resilience	0	28	20/03/201 7
Extracorporeal membrane oxygenation AND Ethics	0	28	20/03/201 7
ECMO AND Ethics	1	29	20/03/201 7
Extracorporeal membrane oxygenation AND Ethical	1	30	20/03/201 7
ECMO AND Ethical	1	31	20/03/201 7
Extracorporeal membrane oxygenation AND Communication	0	31	20/03/201 7
ECMO AND Communication	0	31	20/03/201 7
Extracorporeal membrane oxygenation AND Decision Making	0	31	

Medline	ECMO AND Decision Making	0	31	20/03/201 7
	Extracorporeal membrane oxygenation AND Compassion Fatigue	0	31	20/03/201 7
	ECMO AND Compassion fatigue	0	31	20/03/201 7
	Extracorporeal membrane oxygenation AND Moral Distress	0	31	20/03/201 7
	ECMO AND Moral Distress	0	31	20/03/201 7
	Extracorporeal membrane oxygenation AND Malfunction	1	32	23/03/201 7
	ECMO AND Malfunction	0	32	23/03/201 7
	Extracorporeal membrane oxygenation AND Error	0	32	23/03/201 7
	ECMO AND Error	0	32	23/03/201 7
	Extracorporeal membrane oxygenation AND Staff AND Experiences	0	32	20/03/201 7
	ECMO AND Staff AND Experiences	0	32	20/03/201 7

Extracorporeal Membrane Oxygenation AND Nurse AND Experiences	0	32	20/03/201 7
ECMO AND Nurse AND Experiences	0	32	20/03/201 7
Extracorporeal Membrane Oxygenation AND Doctor AND Experiences	0	32	20/03/201 7
ECMO AND Doctor AND Experiences	0	32	20/03/201 7
Extracorporeal Membrane Oxygenation AND Physician AND Experiences	0	32	20/03/201 7
ECMO AND Physician AND Experiences	0	32	20/03/201 7
Extracorporeal membrane oxygenation AND Psychological	0	32	20/03/201 7
ECMO AND Psychological	0	32	20/03/201 7
Extracorporeal membrane oxygenation AND Stress	0	32	20/03/201 7
ECMO AND Stress	0	32	20/03/201 7
Extracorporeal membrane oxygenation AND Burnout	0	32	20/03/201 7
ECMO AND Burnout	0	32	20/03/201 7

Extracorporeal membrane oxygenation AND Coping	0	32	21/03/201 7
ECMO AND Coping	0	32	21/03/201 7
Extracorporeal membrane oxygenation AND Growth	0	32	21/03/201 7
ECMO AND Growth	0	32	21/03/201 7
Extracorporeal membrane oxygenation AND Resilience	0	32	21/03/201 7
ECMO AND Resilience	0	32	21/03/201 7
Extracorporeal membrane oxygenation AND Ethics	10	42	21/03/201 7
ECMO AND Ethics	0	42	21/03/201 7
Extracorporeal membrane oxygenation AND Ethical	2	44	21/03/201 7
ECMO AND Ethical	0	44	21/03/201 7
Extracorporeal membrane oxygenation AND Communication	2	46	21/03/201 7
ECMO AND Communication	0	46	21/03/201 7
Extracorporeal membrane oxygenation AND Decision Making	0	46	

Psyc INFO	ECMO AND Decision Making	0	46	
	Extracorporeal membrane oxygenation AND Compassion Fatigue	0	46	21/03/201 7
	ECMO AND Compassion fatigue	0	46	21/03/201 7
	Extracorporeal membrane oxygenation AND Moral Distress	0	46	21/03/201 7
	ECMO AND Moral Distress	0	46	21/03/201 7
	Extracorporeal membrane oxygenation AND Malfunction	1	47	23/03/201 7
	ECMO AND Malfunction	0	47	23/03/201 7
	Extracorporeal membrane oxygenation AND Error	1	48	23/03/201 7
	ECMO AND Error	0	48	23/03/201 7
	ECMO	0	48	21/03/201 7
	Extracorporeal Membrane Oxygenation	0	48	21/03/201 7
	ECMO	0	48	21/03/201 7
	Extracorporeal Membrane Oxygenation	0	48	21/03/201 7
Psyc Articles				

Academic Search Complete	Extracorporeal membrane oxygenation AND Staff AND Experiences	1	49	21/03/201 7
	ECMO AND Staff AND Experiences	0	49	21/03/201 7
	Extracorporeal Membrane Oxygenation AND Nurse AND Experiences	1	50	21/03/201 7
	ECMO AND Nurse AND Experiences	0	50	21/03/201 7
	Extracorporeal Membrane Oxygenation AND Doctor AND Experiences	0	50	21/03/201 7
	ECMO AND Doctor AND Experiences	0	50	21/03/201 7
	Extracorporeal Membrane Oxygenation AND Physician AND Experiences	0	50	21/03/201 7
	ECMO AND Physician AND Experiences	0	50	21/03/201 7
	Extracorporeal membrane oxygenation AND Psychological	1	51	21/03/201 7
	ECMO AND Psychological	0	51	21/03/201 7

Extracorporeal membrane oxygenation AND Stress	0	51	21/03/201 7
ECMO AND Stress	0	51	21/03/201 7
Extracorporeal membrane oxygenation AND Burnout	0	51	21/03/201 7
ECMO AND Burnout	0	51	21/03/201 7
Extracorporeal membrane oxygenation AND Coping	0	51	21/03/201 7
ECMO AND Coping	0	51	21/03/201 7
Extracorporeal membrane oxygenation AND Growth	1	52	21/03/201 7
ECMO AND Growth	0	52	21/03/201 7
Extracorporeal membrane oxygenation AND Resilience	1	53	21/03/201 7
ECMO AND Resilience	0	53	21/03/201 7
Extracorporeal membrane oxygenation AND Ethics	0	53	21/03/201 7
ECMO AND Ethics	0	53	21/03/201 7
Extracorporeal membrane oxygenation AND Ethical	0	53	21/03/201 7
ECMO AND Ethical	0	53	21/03/201 7

Extracorporeal membrane oxygenation AND Communication	0	53	21/03/201 7
ECMO AND Communication	0	53	21/03/201 7
Extracorporeal membrane oxygenation AND Decision Making	0	53	21/03/201 7
ECMO AND Decision Making	1	54	21/03/201 7
Extracorporeal membrane oxygenation AND Compassion Fatigue	0	54	21/03/201 7
ECMO AND Compassion fatigue	0	54	21/03/201 7
Extracorporeal membrane oxygenation AND Moral Distress	0	54	21/03/201 7
ECMO AND Moral Distress	0	54	21/03/201 7
Extracorporeal membrane oxygenation AND Malfunction	0	54	23/03/201 7
ECMO AND Malfunction	0	54	23/03/201 7
Extracorporeal membrane oxygenation AND Error	0	54	23/03/201 7
ECMO AND Error	0	54	23/03/201 7



SCOPUS	Extracorporeal membrane oxygenation AND Staff AND Experiences	1	55	21/03/201 7
	ECMO AND Staff AND Experiences	1	56	21/03/201 7
	Extracorporeal Membrane Oxygenation AND Nurse AND Experiences	0	56	21/03/201 7
	ECMO AND Nurse AND Experiences	0	56	21/03/201 7
	Extracorporeal Membrane Oxygenation AND Doctor AND Experiences	0	56	21/03/201 7
	ECMO AND Doctor AND Experiences	0	56	21/03/201 7
	Extracorporeal Membrane Oxygenation AND Physician AND Experiences	1	57	21/03/201 7
	ECMO AND Physician AND Experiences	1	58	21/03/201 7
	Extracorporeal membrane oxygenation AND Psychological	0	58	21/03/201 7
	ECMO AND Psychological	0	58	21/03/201 7

Extracorporeal membrane oxygenation AND Stress	0	58	21/03/201 7
ECMO AND Stress	0	58	21/03/201 7
Extracorporeal membrane oxygenation AND Burnout	0	58	21/03/201 7
ECMO AND Burnout	0	58	21/03/201 7
Extracorporeal membrane oxygenation AND Coping	0	58	21/03/201 7
ECMO AND Coping	0	58	21/03/201 7
Extracorporeal membrane oxygenation AND Growth	0	58	21/03/201 7
ECMO AND Growth	0	58	21/03/201 7
Extracorporeal membrane oxygenation AND Resilience	0	58	21/03/201 7
ECMO AND Resilience	0	58	21/03/201 7
Extracorporeal membrane oxygenation AND Ethics	1	59	21/03/201 7
ECMO AND Ethics	0	59	21/03/201 7
Extracorporeal membrane oxygenation AND Ethical	0	59	21/03/201 7
ECMO AND Ethical	0	59	21/03/201 7

Extracorporeal membrane oxygenation AND Communication	0	59	21/03/201 7
ECMO AND Communication	0	59	21/03/201 7
Extracorporeal membrane oxygenation AND Decision Making	0	59	21/03/201 7
ECMO AND Decision Making	0	59	21/03/201 7
Extracorporeal membrane oxygenation AND Compassion Fatigue	0	59	21/03/201 7
ECMO AND Compassion fatigue	0	59	21/03/201 7
Extracorporeal membrane oxygenation AND Moral Distress	0	59	21/03/201 7
ECMO AND Moral Distress	0	59	21/03/201 7
Extracorporeal membrane oxygenation AND Malfunction	0	59	23/03/201 7
ECMO AND Malfunction	0	59	23/03/201 7
Extracorporeal membrane oxygenation AND Error	0	59	23/03/201 7
ECMO AND Error	0	59	23/03/201 7

**6.2. Appendix B – Ethics Review Decision Letter****School of Psychology Research Ethics Committee****NOTICE OF ETHICS REVIEW DECISION****For research involving human participants**

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**REVIEWER:** Volker Thoma

**SUPERVISOR:** Kenneth Gannon

**COURSE:** Professional Doctorate in Clinical Psychology

**STUDENT:** Joshua Wellman

**TITLE OF PROPOSED STUDY:** Staff experiences of extracorporeal membrane oxygenation (ECMO).

**DECISION OPTIONS:**

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

**DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY**

*(Please indicate the decision according to one of the 3 options above)*

Approved

**Minor amendments required** *(for reviewer):*

**Major amendments required** *(for reviewer):*

**ASSESSMENT OF RISK TO RESEACHER** *(for reviewer)*

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

- ☐ HIGH
- ☐ MEDIUM
- ☒ LOW

*Reviewer comments in relation to researcher risk (if any):*

**Reviewer** *(Typed name to act as signature):*

Volker Thoma

**Date:** 10/5/2015

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee*

**Confirmation of making the above minor amendments** *(for students):*

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*

Student number:

Date:

*(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

**PLEASE NOTE:**

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: <http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

### 6.3. Appendix C - Health Research Authority Approval Notification



**Health Research Authority**

**Mr Josh Wellman**  
 Trainee Clinical Psychologist  
 School of Psychology  
 University of East London  
 Water Lane, London  
 E15 4LZ

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

25 August 2016

Dear Mr Wellman,

**Letter of HRA Approval**

<b>Study title:</b>	<b>An exploration of staff experiences of extracorporeal membrane oxygenation</b>
<b>IRAS project ID:</b>	<b>199865</b>
<b>REC reference:</b>	<b>16/HRA/2086</b>
<b>Sponsor</b>	<b>University of East London</b>

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

## 6.4. Appendix D – Letter of Indemnity and Sponsorship



1<sup>st</sup> September 2016

Dear Joshua,

<b>Project Title:</b>	<b>An exploration of staff experiences of extracorporeal membrane oxygenation</b>
<b>Researcher(s):</b>	<b>Joshua Wellman</b>
<b>Principal Investigator:</b>	<b>Joshua Wellman</b>

I am writing to confirm that the application for the aforementioned NHS research study reference **16/HRA/2086** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **1<sup>st</sup> September 2020**. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why UREC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Trust Research Ethics Committee by emailing [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk).

**Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.**

With the Committee's best wishes for the success of this project.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Catherine Fieulleateau'.

**Catherine Fieulleateau**  
**Research Integrity and Ethics Manager**  
 For and on behalf of  
 Dr Lisa Mooney  
 University Research Ethics Committee (UREC)  
 Research Ethics  
 Email: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk)



## 6.5. Appendix E – Initial Email to Potential Participants

Dear [Insert Staff Member Name],

Dr (Insert Field Supervisor Name), Consultant Clinical Psychologist and Josh Wellman, Trainee Clinical Psychologist, are currently recruiting staff working on AICU at [insert hospital name], to participate in a qualitative research study focusing on staff experiences of working with ECMO. The research is being conducted for a doctoral thesis, to date there are no publications in this area.

We have recently received ethical and research and development approval for the project and are currently seeking six doctors and six nurses to participate in the research, which consists of a one hour interview, all research data will be anonymised. The interviews will take place in in October, November and December at [Insert Hospital Name].

You have been identified by your colleagues as a professional who has extensive experience in this area of work and therefore we would like to offer you an opportunity to participate. By participating, you will help to guide the development of policy and clinical practice in this area of work.

If you are interested in participating or would like to discuss the research further, please either reply directly to this email or contact:

Josh Wellman - [Insert Trust Email Address], [Insert Telephone Number]

or

Dr [Insert Field Supervisor Name] - [Insert Trust Email Address], [Insert Telephone Number].

Kind regards

Josh Wellman  
Trainee Clinical Psychologist

Supervised by  
Dr [Insert Field Supervisor Name]  
Consultant Clinical Psychologist

## **6.6. Appendix F – Description of Conceptual Depth Criteria and their Application to this Research**

Nelson (2016) describes five criteria that indicate whether the data collected, provide enough depth and quality to adequately answer the research question posed in a qualitative study and have good applicability to a wider context. Nelson's (2016) self-assessment criteria were utilised to rate the conceptual depth of this research. Each criterion was rated on a three-point scale: low, medium or high.

**Range:** A high frequency of codes were noted for many concepts identified in the coding frame. This included the multiple instances of the same code, but also variations within the code, indicating that differing views were expressed in relation to the same topic. Appendix M provides an example of this directly from the coding frame. (Criterion Satisfied: Rating high).

**Complexity:** Maps and diagrams were used to analyse the data and consider how codes began to fit together into broader codes, subthemes and themes. Appendix N provides some examples of the maps used to analyse data and demonstrates how concepts began to merge together into subthemes and themes. (Criterion Satisfied: Rating high).

**Subtlety:** After codes were grouped together in the coding frame, they were re-visited by the researcher, in order to consider the extent of contradictions, ambiguity and distinctiveness in participant views. This process led to the breaking up of the 'medical decisions' theme (see appendix N) with the realisation that groups of codes relating to ethical challenges were a better fit in 'team spirit' and 'the paradox of feeling masterful and inept' subthemes. However, it may have been useful to document further evidence of this process using memos. (Criterion Satisfied: Rating medium).

**Resonance:** The data at coding and thematic level fits with the professional, ethical and clinical practice issues identified in broader academic literature relating to intensive care and ECMO. Novel findings on the whole, could also be explained using existing psychological theory. (Criterion Satisfied: Rating High).

**Validity:** Early analysis and coding were checked with the director of studies (DOS) for the thesis and final themes and interpretations discussed and verified, to ensure that they were abstract, independent from the research and interview questions and had applicability beyond the immediate context in which the research was conducted. (Criterion Satisfied – Rating High)

## 6.7. Appendix G – Participant Information Sheet

University of East London School of Psychology  
Stratford Campus  
Water Lane  
London E15 4LZ

### Participant Information Sheet

#### The Principal Investigator(s)

Name of researcher: Mr Joshua Wellman

Contact Details: [Insert Trust Email Address], [Insert Contact Telephone Number].

#### Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider when deciding whether to participate a research study. The study is being conducted as part of Joshua Wellman's Professional Doctorate in Clinical Psychology, at the University of East London.

#### Project Title

An exploration of staff experiences of extracorporeal membrane oxygenation (ECMO)

#### What is the research about?

This research project aims to find out about the experiences of healthcare staff that have worked clinically with patients being treated with extracorporeal membrane oxygenation (ECMO). ECMO is considered a life saving treatment, given in an intensive care setting when people are critically ill. ECMO and the circumstances under which it is used, presents challenges to clinicians, patients and relatives. This research aims to find out more about how staff experience ECMO in the context of patient care. Key areas that will be covered will include medical decision-making, challenges with patient care, supporting relatives, the psychological impact of these factors on staff and ways of coping with them.

#### Am I able to participate?

This research is being conducted on the intensive care unit at the [Insert Hospital Name]. If you are an intensive care doctor (of any grade) or a qualified nurse and have worked with patients being treated with ECMO, we would be keen to hear about your experiences.

#### What will taking part involve?

You will be invited to attend an interview lasting approximately 60 minutes. You will be asked questions about your experience of working with patients and families in the context of ECMO treatment. Interviews will take place at [Insert Hospital Name] or the University of East London (Stratford Campus), depending on your preference.

#### What are the benefits of participating?

By participating in this research you will help to identify key challenges, potential psychological implications and ways of coping with this work. Your participation could help to guide best practice (e.g. support mechanisms) for staff working with patients being treated with ECMO. In addition, working on an intensive care unit and with life-saving technologies such as ECMO, can be emotionally exhausting. Some staff may find talking through such experiences to be beneficial, helping them to make sense of their experiences and the impact on their lives.

**Are there any disadvantages to participating?**

Some people can find talking about stressful and challenging situations to be upsetting, and doing so may bring up difficult feelings. If this happens during or after the interview you can discuss any concerns that you have with the researcher and options for follow up support will be provided. For example, attending reflective practice groups or staff counselling support. You will also be entitled to take a break during the interview, reschedule the interview for a later date or withdraw from the interview at any time of your choosing.

**What else do I need to be aware of when deciding whether to participate?**

You do not have to participate in this research. Your choice to participate or not will have no impact on your employment with the trust. The research has been reviewed by the University of East London research ethics committee, who have deemed that this research adequately protects your rights, safety, well-being and dignity.

**Confidentiality**

The data that you provide will only be accessible to the researcher and research supervisors and will not be shared with others. The interview will be audio recorded and then transcribed and your data will be stored digitally on a password-protected computer. Your name will be removed from all transcripts and any reports that are written, so that you remain anonymous. Once the study has been completed, the audio recording from our interview will be deleted, but the anonymised transcriptions may be stored for up to three years.

**How will the results of the research be shared with others?**

A summary of the findings will be shared with participants and managers in order to inform best practice on the department. This will be completely anonymised. The research will be submitted for publication to an academic journal and will be reported in a thesis, which will be publically available from the University of East London's institutional repository.

**Disclaimer**

You are free to withdraw from this study at any time without disadvantage to yourself and without any obligation to give a reason. However, should you choose to withdraw once data analysis has commenced, the researcher reserves the right to use your anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.

**If I need to make a complaint, how can I do so?**

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor [Dr Kenneth Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020 8223 4576. Email: K.N.Gannon@uel.ac.uk]

**or**

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mary Spiller, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Tel: 020 8223 4004. Email: m.j.spiller@uel.ac.uk)

**What if I have further questions?**

If you have any questions you can contact me using the details provided at the top of this document, or alternatively Dr [Insert Field Supervisor Name] (Consultant Clinical Psychologist). If you have any general questions about participating in research within the trust, you can obtain this by contacting the research team through the following email address [Insert Email Address].

**What next?**

If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

Thank you in participation.

Yours sincerely,

[Joshua Wellman, Insert Date]

**6.8. Appendix H – Consent Form****Consent Form****UNIVERSITY OF EAST LONDON****Consent to participate in a research study**

An exploration of staff experiences of extracorporeal membrane oxygenation (ECMO)

I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. I understand the limits of confidentiality and that if criminal or ethical issues in relation to patient care are raised within the interview, this will be addressed according to trust policy. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study, which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I understand that in the event that I decide to withdraw after the researcher has begun analysing my interview data, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Date: .....

**6.9. Appendix I – Participant Demographic Form****Demographic information**

- 1. What is your age?**
  
- 2. What is your Gender?**
  
- 3. What is your professional grade (e.g. Staff Nurse)?**
  
- 4. For how many years have you been working with ECMO patients?**
  
- 6. Have you had any specialist ECMO training (e.g. retrieval)? If so, please also describe the training you have received:**

- 5. Please circle an option that best describes your ethnic background:**

**White**

British

Irish

Any other European background (Please describe): \_\_\_\_\_

Any other White Background (please describe): \_\_\_\_\_

**Mixed/Multiple ethnic groups**

White and Black Caribbean

White and Black African

White and Asian

Any other Mixed/Multiple Ethnic Background (please describe): \_\_\_\_\_

**Asian/Asian British**

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian Background (please describe): \_\_\_\_\_

**Black/African/Caribbean/Black British**

African

Caribbean

Any other Black/African/Caribbean background (please describe):

\_\_\_\_\_

**Other Ethnic Group**

Arab

Any other Ethnic Group (please describe): \_\_\_\_\_



## **6.10. Appendix J – Interview Schedule**

### **Interview Schedule**

This interview schedule provides a guideline for questioning during individual staff interviews. It outlines key areas of interest to the researcher.

#### **General experience of ECMO**

- How is ECMO involved in your work as an ICU (add professional title).
- What are your specific duties and responsibilities in relation to ECMO?  
(Prompts: direct care with patients, family support, medical decision-making, ECMO retrieval).
- Tell me about your views on ECMO as a treatment (Prompt: positive or negative perspectives).
- How has ECMO impacted treatment practices and your work as a (professional title) on intensive care?

#### **Psychological impact – Preface that it's ok to think about a particular case or cases or incident when answering these questions**

- What are some of the most stressful or challenging aspects of working with ECMO (prompts: impact on patients, impact on family, impact on individual staff, or the staff team)

##### **Prompt**

Particular types of patient/relative challenging to work with  
Challenges amongst the team.  
Working conditions.

- How do these challenges impact you?
- How does it impact other staff, or the broader multidisciplinary team?
- How does working with ECMO compare with other tasks or treatments on intensive care?

If answers focus on negative impacts of ECMO, use this follow up question:

- Are there ever times when working with ECMO works smoothly and easily?
- Are there any positive implications or aspects of working with ECMO?
- How does this impact you, other staff, the broader team?

#### **Personal, social and organisational resources**

- How do you manage the challenges of this work?
- How do other staff manage the challenges of this work?
- What support is available to manage the challenges of this work? (prompts: organisational and social resources).
- Is there any other support that could be made available, or would be helpful?

#### **Closing question**

Summarise what has been discussed.

Is there anything else that is important for me to know about your work with ECMO?

**Debrief discussion**

How did you find participating in the interview?

Is there anything that came up that you would like to discuss further?

**Give debrief form**

**6.11. Appendix K – Interview Debrief Form****Debrief Form**

Thank you for your participation in this research study, focusing on staff experiences of ECMO. This sheet provides you with information about services that can offer further support following on from your interview, if you require. Intensive care staff have commonly found these services to be a useful means of obtaining emotional and psychological support.

**Staff Counselling Support**

Staff counselling support services can be accessed through the occupational health service at the [Insert Hospital Name]. To access this service you should initially make an appointment with the occupational health team, who will discuss your personal situation and make an onward referral on your behalf, if necessary. Telephone: [Insert Telephone Number].

**Reflective Practice on Intensive Care**

Reflective practice sessions are run on the intensive care ward. They offer an opportunity to highlight any concerns. If you would like to participate, please contact your line manager to find out about the next planned session, or alternatively Dr [Insert Field Supervisor Name] (Consultant Clinical Psychologist). Contact: [Insert Contact Email Address]

**Counseling of Psychological support**

If you would like to access counselling or psychological support outside of the trust, please contact your General Practitioner (GP) to discuss this further.

For further clarification on any information in this sheet, please contact [Insert researcher's contact email address] prior to April 2017.

## 6.12. Appendix L – Example of Coding from Original Data Corpus

221	[things. So, how much blood are you going to give to them. Before	
222	we gave them a lot of blood, we gave them like a 10 of	
223	haemoglobin, now ninety is fine, or eighty something is fine, we	
224	don't transfuse and transfuse to them any more. And we have much	
225	more control of our anticoagulation as well. So I think	
226	experience will teach us, the more experience you have in doing	Complex Care –
227	this kind of work, the better.	Learning Through Experience
228	I: Yeah, so the technology is very helpful, but the experience of the	
229	staff is also very important. ]	Training Important –
230	[N1: Yes, it is very important as well, and also training, lots of	
231	training just helps you understand it, so that you can safely deal with	Safe Practice
232	the patients.]	
233	[I: Is there any way in the team that you determine someone's	
234	experience? Is it number of years, amount of training that you've	
235	done, or number of patients that you've seen?	Training - Technical Knowledge – Machine/Physiology
236	N1: I think it's a combination of everything. First of all you have to	
237	be trained. You have to have the knowledge, the understanding of	
238	how this machine works and the physiology around it, you have to	
239	understand that.]	
240	I: Yeah	
241	[N1: Then you have the skills, the skills to become competent in	
242	using this machine. How to take care of the tubings and everything	Technical skills/Competence
243	else.] [And then, also the emergency, you have to be trained, you	
244	have to be skilful in dealing with those things as well. The more you	Managing Emergency- Personal Experience
245	are exposed to it, the more you can handle it. Its good to have	
246	experience of dealing with the emergency situations, you gain	
247	something from it, as long as it doesn't traumatise you.]	Positive - Learning
248	I: Yeah	
249	[N1: You will learn from it, from those experiences. Sometimes I ask	
250	myself, ok, I was taught how to do this, but I haven't tested if I can	Managing Emergency- Personal Experience – Testing Abilities
251	deal with it because I haven't had experience of how to deal with	
252	this incident. So maybe in my head it's in there, but in an actual	
253	situation, I have not really done it.] [So the test is, I don't really want	
254	to have that test, I don't want this machine to stop completely and	
255	I have to remove it from him and put it on the (?).] [But maybe I	
256	can do it, because I am imagining it in my head. But of course, when	Managing Technical - Emergency- Anxiety
257	it's in a real situation you will be emotionally charged during that	
258	time.]	Managing Technical -Emergency – Ability Uncertain – Emotionally Charged

### 6.13. Appendix M – Example of Coding Frame

This example from the coding frame demonstrates the variety of codes assigned to data describing nurses views on formal emotional support available to them, in the form of nurse team days.

Table v. Example of codes, spliced codes, subthemes and themes from the coding frame.

Theme	Subtheme	Spliced Code	Code
Emotional Rollercoaster	Managing Emotions	Formal Support for Expressing Emotions	Emotional Expression - Space to Share Feelings Important - Nurse Team Days
			Emotional Expression - Space to Share Feelings Important - Nurse Team Days – Work Depressing
			Emotional Expression - Space to Share Feelings - Nurse Team Days - Psychologists think It's Helpful
			Emotional Expression - Space to Share Feelings - Nurse Team Days - Helpful
			Nurse Team Days - Share Negative Feelings - Unhelpful
			Nurse Team Days Should have Positive Focus

### 6.14. Appendix N – Thematic Maps Explaining Thematic Development

Small segments of data from transcripts were initially coded diversely. Codes broadly fell into the groups indicated in figure i. Lines indicate which groups of codes linked together.

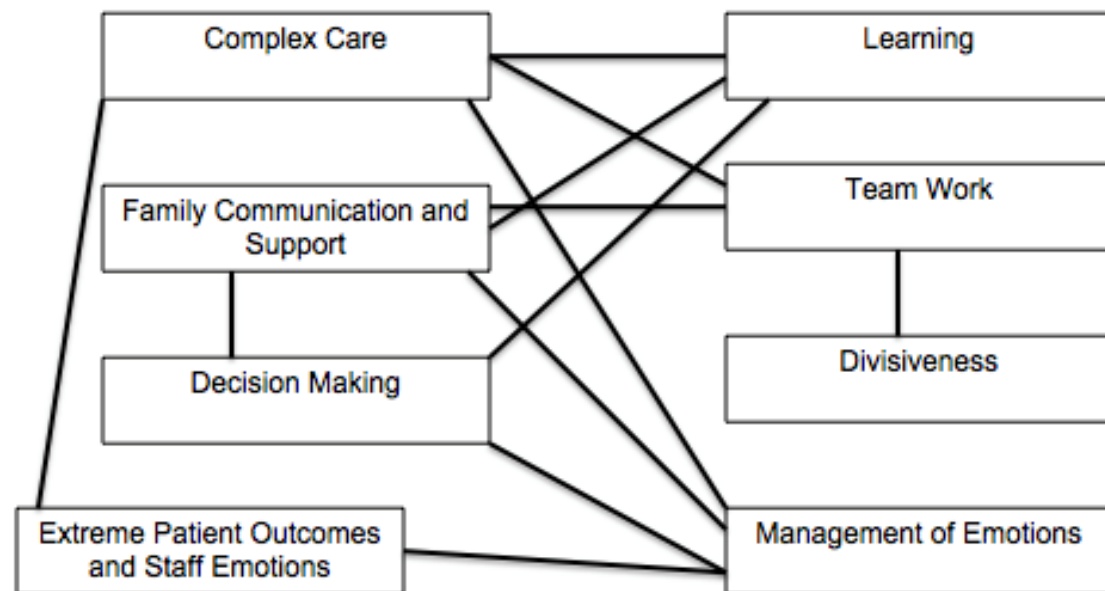


Figure i. Broad code groupings after initial coding of data.

Codes were ordered into 'super-codes' in the coding frame, and were then grouped into the interim themes and subthemes indicated in figure ii.

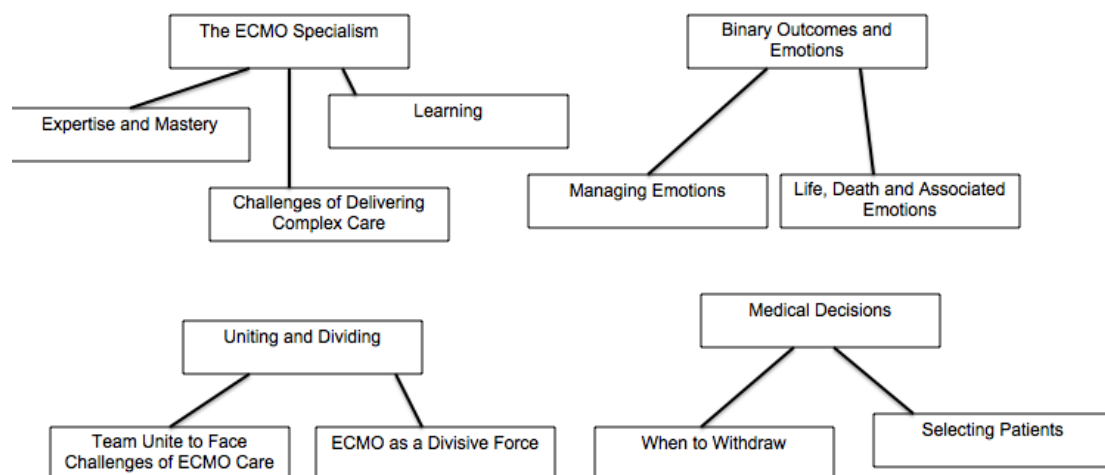


Figure ii. Interim thematic map following grouping of codes.

Aspects of the 'medical decisions' theme (see figure ii above) pervaded other themes. For example, some codes in the 'selecting patients' and 'when to withdraw' subthemes related to challenging decisions that were made by

clinicians as a team and therefore fell into the 'team spirit' subtheme of 'team dynamics' in the thematic map below. There was also significant uncertainty around 'when to withdraw' or continue treatment and in relation to 'selecting patients' for ECMO. Therefore other codes in these subthemes were moved into 'the paradox of feeling masterful and inept' subtheme of 'embodying the ECMO specialist' theme in the map below (see figure iii.). As such codes in the 'medical decisions' theme were broken up and redistributed, reducing the number of themes from Four to Three.

Super-ordinate themes and subthemes from figure ii. were renamed following the addition of new data from the 'medical decisions', to account for other smaller sets of codes that were moved between subthemes, or because a differing theme/subtheme title was thought to better represent the existing data. The final thematic map is illustrated in figure iii.

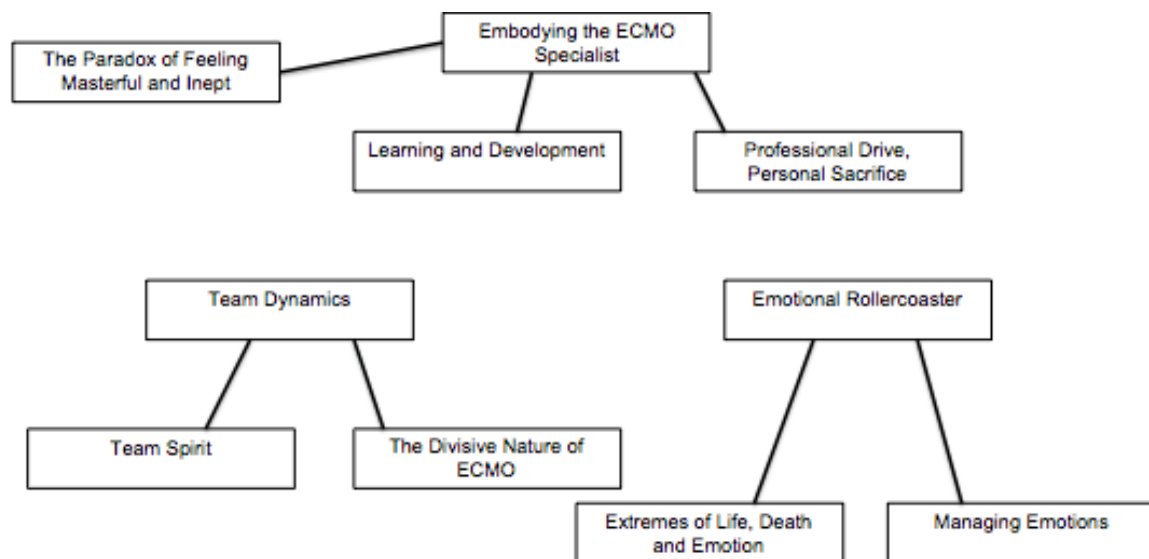


Figure iii. Final thematic map.