Terminal Weaning and Terminal Extubation within the Context of End-of-Life Care in the Intensive Care Unit: A Quantitative Descriptive Analysis of Recent Practices

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Preface

Ethical Approval Obtained to Conduct Research

This Master's thesis is a secondary data analysis. Ethical approval for the primary study was received from the Research Ethics Board associated with the study site. Approval was also obtained from the University of Ottawa Research Ethics Board.

Statement of Contributions and Co-Authorship

Multiple authors contributed to this thesis and the associated manuscript. The contributions of each author are outlined below.

1. Mustafa Al-Janabi, BScN RN, *Master of Science in Nursing student, School of Nursing, Faculty of Health Sciences*. This research was completed for my master's thesis. I acted as the lead research assistant on the primary study. I wrote and revised all chapters within this thesis and am the primary author of the manuscript in Chapter 4.

2. Brandi Vanderspank-Wright, PhD RN CNCC(C), *Associate Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa and Affiliate Investigator, the Ottawa Hospital Research Institute*. Dr. Vanderspank-Wright, acted as my thesis supervisor and also the Principal Investigator for the primary study. She provided ongoing support and feedback throughout the conception and completion of this research. She helped identify the research question and purpose for this secondary analysis. Additionally, she contributed to the research design, literature review, and data-analysis, and critically revised every chapter of this thesis. She is the senior author of the manuscript in Chapter 4.

3. Michelle Lalonde, PhD RN, *Associate Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa*. Dr. Lalonde, acted as a thesis committee member, offered

substantive guidance in the research design and data analysis. She also provided input for data analysis, and she critically revised every chapter of this thesis.

4. Nikolaos Efstathiou, PhD RN, *Lecturer, School of Nursing, University of Birmingham, Birmingham, UK*. Dr. Efstathiou, acted as a thesis committee member and is a Co-Investigator on the Primary Study. Dr. Efstathiou helped identify the research questions and purpose and offered guidance and substantive feedback on the research design and data analysis. He critically revised every chapter of this thesis.

Abstract

Background: The withdrawal of invasive mechanical ventilation (MV) within the context of withdrawal of life-sustaining measures (WLSM) is common in the intensive care unit (ICU). The method by which invasive MV is withdrawn during WLSM remains an ongoing topic of discussion and research; two methods are terminal weaning (TW) and terminal extubation (TE).

Aims: To statistically describe and compare the processes of TW and TE as undertaken in two ICUs.

Study Design: A secondary data analysis using data from a longitudinal retrospective chart audit.

Results: A total of 78 patient charts were included. MV was withdrawn in 88.5% of patients undergoing WLSM. TW was used in 62.3% of the cases while TE was used in 37.7%. Patients who underwent TW were on average younger, had a longer ICU stay, higher respiratory support requirements, a longer duration of invasive MV, and shorter period from first change in MV parameters to patient death.

Conclusion: This study highlights the nuances and complexities within MV withdrawal and WLSM in the ICU.

Keywords: Withdrawal of Life-Sustaining Measures, Mechanical Ventilation, Terminal Weaning, Terminal Extubation, Intensive Care Unit, Critical Care

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Table of Contents

Tables and Figures

Chapter 1

Chapter 2

Chapter 3

Chapter 4

Chapter 5

Chapter 1: Introduction

Background

On a yearly basis, there are more than 230,000 admissions to adult intensive care units (ICU) in Canada (Canadian Institute for Health Information, 2016). Patients are admitted for a variety of reasons related to critical illness, including the need for close observation and intense monitoring, and for situations that necessitate the use of invasive treatments and life-sustaining measures (LSM). The predominant LSM is advanced airway support including endotracheal intubation and mechanical ventilation (MV) (Marshall et al., 2017). However, despite interventions and the provision of high-quality critical care, patients often succumb to critical illness and die while in the ICU. The most recent data available through the Canadian Institute of Health Information (CIHI) (2016) reported that the mortality rate for Canadian ICU patients for the year of 2013-2014 was 9%. Worldwide, however, ICU mortality rates range from 6% in Germany (Kaben et al., 2008), to 10% in the United States (Wunsch et al., 2011). In the England, Wales and Northern Ireland, the Intensive Care National Audit and Research Centre (ICNARC) reported an ICU mortality rate of 13.9% for patient admitted to ICU during the period from April 2019 to March 2020 (ICNARC, 2020). Current statistical information from the Society of Critical Care Medicine (SCCM) indicates that mortality rates vary from 10 to 29% (SCCM, n.d.), but it should be noted that the most recent reference supporting this statement is from 2017. Accordingly, these rates do not take into account the impact of the COVID-19 global pandemic on ICU mortality rates.

Importantly, because of the use of LSM that critical illness necessitates, dying in the ICU *often* follows a shared decision-making process whereby informed decisions are made between substitute decision makers and the health care team to discontinue and subsequently withdraw the use of LSM, including MV (Dean et al., 2010; Hans, 2009; Thellier et al., 2017; Wiegand &

Petri, 2010). While this is the case in many ICUs across the globe (e.g., Canada, United States, United Kingdom), it is important to highlight that the withdrawal of LSM is not a universally adopted practice. For example, in Japan, the withdrawal of MV is rarely practiced as it is thought of as a life-shortening procedure, and accordingly, legally prohibited (Aita & Kai, 2010).

MV is a LSM that is offered to patients at risk of, or undergoing failure of the respiratory system, such as patients with airway compromise, as well as lung infections and lung injuries that impact oxygenation and ventilation (Maiden, 2018). MV can be non-invasive, such as bilevel positive airway pressure ventilation (BiPAP), or invasive requiring endotracheal tube insertion and MV (Poor, 2018). Invasive ventilation is the focus of this thesis, more specifically, practices related to the withdrawal of invasive MV within the context of withdrawal of life-sustaining measures (WLSM) at the end-of-life in the ICU.

Downar and colleagues worked with the Canadian Critical Care Society (CCCS) and the Canadian Association of Critical Care Nurses (CACCN) to develop and publish guidelines specific to the WLSM (Downar et al., 2016). They remarked that the guidelines were necessary given that despite the availability of published clinical recommendations, the process of WLSM varies considerably across ICUs and among clinicians globally (Downar, et al., 2016). Using a modified Delphi approach, the authors developed guidelines specific to four domains: *preparing for withdrawal of life-sustaining measures, assessment of distress, pharmaceutical management of distress*, and *discontinuation of life-sustaining measures and monitoring*. Due to the limitations of evidence to support particular practices, Downar et al. (2016) used the following grading system: ‘We recommend’ was used for practices that are supported by multiple studies and were consistent with the countries’ legal and ethical framework; ‘We suggest’ was used for practices supported by one study or expert opinion and is consistent with legal and ethical values.

Recommendation 4.4 of the guideline is specific to the discontinuation of ventilation and is informed by limited evidence. The authors state the following:

> *We recommend*
> Sequence and process should be individualized with comfort as the goal
> Mechanical ventilation should be withdrawn as quickly as comfort will allow
> Patients should not be routinely extubated to non-invasive ventilation
> *We suggest*
> In most cases, the goal should be to extubate patients to room air
> Extubation is preferable to leaving the patient intubated at the end of a wean, but either is acceptable. (p.102)

As a result, while the guidelines necessarily encourage individualized care and make suggestions regarding weaning and extubation, variability exists within the guideline itself. There is also little guidance as to what these sequences and processes ought to look like. In addition to the variability and ambiguity noted in the 2016 guidelines, ambiguity is also noted in the literature (Cottereau et al., 2016; Efstathiou et al., 2020; Robert et al., 2017) and there is limited evidence to suggest what best practices are for terminal weaning and terminal extubation within the context of end-of-life care in the ICU.

Terminal Weaning and Terminal Extubation

The recommendations put forth by Downar et al. (2016) refer to two processes of withdrawing ventilatory support: terminal weaning (TW) and terminal extubation (TE). While under usual critical care circumstances, weaning and extubation are regular and necessary practices, the use of the word ‘terminal’ in this instance is purposeful. Terminal in this regard is representative of a practice that will not be reversed (i.e., a patient experiencing increased work of breathing and possible respiratory distress following extubation will not be re-intubated) and that is likely done within the context of WLSM (Hui et al., 2014). TW involves stepwise, gradual reductions in oxygen and ventilatory support (e.g., decreasing supplemental oxygen and/or

decreasing support provided by the mechanical ventilator) with the end target being the termination of mechanical ventilation and commonly the removal of the endotracheal tube (Cottereau et al., 2016; Efstathiou et al., 2020; Robert et al., 2017). TE involves ceasing ventilatory support and the removal of the endotracheal tube in one-step (Cottereau et al., 2016; Efstathiou et al., 2020; Robert et al., 2017). Tables 1.1 and 1.2 provide visual representations of weaning and extubation practices that were developed based on the definition of TW and TE in the literature.

Table 1.1 Example of Terminal Weaning

Time	Ventilation Parameter
12:00	Mode: Pressure Assist Control Parameters: FiO_2 = 0.50 PS = 18 cm H_2O PEEP = 10 cm H_2O Rate = 16 DP = 20 cm H_2O
12:30 (Start of WLSM)	Mode: Continuous positive airway pressure (CPAP) Parameters: FiO_2 = 0.50 PS = 18 cm H_2O PEEP = 10 cm H_2O
12:45	Mode: CPAP Parameters: FiO_2=0.25 PS= 18 cm H_2O PEEP =10 cm H_2O
13:00	Mode: CPAP Parameters: FiO_2=0.25 PS = 10 cm H_2O PEEP = 10 cm H_2O
13:15	Mode: CPAP Parameters: FiO_2 = 0.25 PS= 8 cm H_2O PEEP=8 cm H_2O
13:30	Mode: T-Piece Parameters: FiO_2=0.21
13:45	Patient extubated to room air.
FiO2: Fraction of inspired oxygen. PS: Pressure support. PEEP: Positive end-expiratory pressure. DP: Driving Pressure.	

Table 1.2 Example of Terminal Extubation

Time	Ventilation Parameter
12:00	Mode: Pressure Assist Control Parameters: FiO_2 = 0.50 PS = 18 cm H_2O PEEP = 10 cm H_2O Rate = 16 DP = 20 cm H_2O
12:30 (Start of the WLSM)	Patient extubated to room air

FiO2: Fraction of inspired oxygen. PS: Pressure support. PEEP: Positive end-expiratory pressure. DP: Driving Pressure.

Study Aim and Objectives

Since the publication of the Downar et al. (2016) guidelines, there has been an effort to standardize WLSM practices across Canadian ICUs. As a result, it can be argued that unit level practices would have potentially changed across the country since 2016. Given this knowledge, and the involvement of some of the research team members in national initiatives, a multi-method study was designed in an effort to capture a current state of WLSM practices specific to TW and TE within two ICUs situated within a large academic health sciences centre. Capturing current state would enable future research to explore and identify change(s) (positive or negative) that may have arisen from the development of the guidelines and subsequent standardization efforts.

The objectives of the multi-method study were to:

1. Conduct a chart audit using a pre-determined extraction tool;
2. Develop an interview guide based on expert opinion and findings from a previously conducted systematic review (Efstathiou et al., 2020);
3. Interview ICU nurses, physicians and respiratory therapists who have been involved in terminal weaning and/or terminal extubation within the context of end-of-life care;

4. Describe the processes, identify factors that influence decision making, explore perceptions among those involved in the process, and identify what support (i.e., educational, organizational, emotional) is required.

This thesis focuses specifically on secondary analysis of data collected to achieve Objective 1 with the aim of: *describing the processes of terminal weaning and terminal extubation within the context of invasive ventilation at the end-of-life across both study sites*.

The thesis objectives are to:

1. Describe in detail the processes of terminal weaning and terminal extubation;
2. Compare, where possible, the similarities and differences in processes and practices across two sites; and,
3. Compare and discuss, where possible, similarities and differences related to the use of comfort care orders at each site and the practices outlined in the comfort care orders protocol.

Thesis Layout

Chapter 1 has introduced the thesis topic including the key concepts of WLSM and TW and TE. In Chapter 1, the thesis purpose and objectives have also been stated.

Chapter 2 provides an overview of literature specific to the context of death and dying in adult ICUs, a more in-depth overview of both the implementation of LSMs and their subsequent withdrawal in the context of end-of-life care. Recent literature on the topic of TW and TE will be explored including findings from a systematic review authored by some members of the primary research team (including myself who worked as a Research Assistant on the review). While this manuscript has not been included as a chapter in this thesis, it is linked to the larger

research project and provides an overview of the current state of TW and TE from a variety of perspectives.

Chapter 3 provides an overview of the research methodology for this thesis, which in this case was a secondary analysis of data and designed as a retrospective, cross-sectional analysis of patient charts for deaths that occurred in 2017 at the study sites. The utility of a secondary analysis is substantiated within the context of the multi-method study.

Chapter 4 presents an unpublished manuscript that has been prepared for submission to Nursing in Critical Care. The manuscript presents the findings of a descriptive analysis of the chart audit data. The empirical findings manuscript satisfies thesis Objectives 1 and 2.

Chapter 5 concludes the thesis with an integrated discussion on the topic. The chapter is divided into two sections; section one discusses the finding of this thesis in relation to Objective 1 and 2. Section two discusses findings related to Objective 3, as well as the role of the ICU nurse in end-of-life care and WLSM. Recommendations for nursing research, practice and education are included.

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Chapter 2: Literature Review

The ICU is the area of specialty practice that provides the context of this research study. In this chapter, I use current literature to discuss the purpose and implementation of LSMs in the ICU as well as how this also intersects with death, dying and end-of-life care. I purposefully examine literature on the WLSM in ICU, with a focus on the withdrawal of invasive MV given its central focus in this thesis. Finally, I discuss TE and TW as methods of MV withdrawal and highlight ICU clinician preferences and practices with respect to this aspect of WLSM.

The Context: Intensive Care and ICUs

This section is primarily informed by the report of the task force of the World Federation of Societies of Intensive and Critical Care Medicine published by Marshall et al. (2017). In this report, intensive care is described as a "multidisciplinary and interprofessional specialty dedicated to the comprehensive management of patients having, or at risk of developing, acute life-threatening organ dysfunction" (Marshall et al., 2017, p. 271). The delivery of such care requires the use of various technologies aimed at supporting the functions of failing organ systems, primarily, the cardiovascular system, the respiratory system, and the renal system (Ferri et al., 2015; Marshall et al., 2017; Nates et al., 2016; Valentin et al., 2011). The core of intensive care expertise is focused on the support of failing or dysfunctioning organs and associated pathophysiology rather than the treatment of a specific disease (Marshall et al., 2017). This expertise enables intensive care clinicians, through the use of specialized interventions, to prevent additional worsening while the underlying condition is addressed and managed (Marshall et al., 2017). The structure and function of care in the ICU includes the following core elements: the environment, equipment and supplies, the ICU team, patients and families, and finally ICU practice itself (Marshall et al., 2017).

The ICU Environment

The ICU environment is a dedicated space deliberately designed for optimal care of patients with acute organ dysfunctions over an extended period of time (Marshall et al., 2017). In general, the layout of this space includes patient rooms, central monitoring stations, equipment and supply storage areas, medication storage areas, education rooms as well as family waiting areas and family meeting rooms (Marshall et al., 2017; Thompson et al., 2012; Valentin et al., 2011). ICU rooms are often single bed spaces with a physical layout that allows for access to the patient's bed from all sides, the incorporation of multiple monitoring devices, and life-supporting equipment (e.g., mechanical ventilators) (Canadian Association of Critical Care Nurses (CACCN), 2019; Ferri et al., 2015; Thompson et al., 2012). Further, ICU rooms generally have large windows that allow constant visibility of the patients as well as all monitors and devices by the health care team.

Equipment and Supplies

A variety of equipment and supplies are required to operate a fully functional ICU including monitoring, supportive, and diagnostic equipment. (Marshall et al., 2017; Nates et al., 2016). Monitoring equipment can be both non-invasive and invasive. Examples of non-invasive monitoring equipment include transcutaneous oxygen saturation, and non-invasive blood pressure cuffs, while arterial blood pressure, intracranial pressure and intraabdominal pressure systems are examples of invasive monitoring (Marshall et al., 2017). Supportive equipment includes devices that are required to provide life-supporting treatments often related to the cardiovascular, the respiratory, or the renal systems (Marshall et al., 2017). Examples include intravenous (IV) infusion pumps used to administer and titrate vasopressors and inotropes, rapid infusers, equipment used for oxygen supplementation (e.g., oxygen masks and ambu bags),

mechanical ventilators, and hemodialysis machines. Finally, the third type of equipment in the ICU is used for the purpose of investigation and diagnosis. Examples of such devices include ultrasound and electrocardiograph machines, scopes, and on-site laboratories (e.g., arterial blood gas labs) (Marshall et al., 2017; Nates et al., 2016). The use of multiple forms of equipment as well as the various alarms and sound notifications associated with this equipment contributes to the ICU being a particularly noisy environment (Stafford et al., 2014).

Supplies used in the ICU include all consumables required to care for the patients, monitor their physiological condition, establish, and maintain life-supporting treatments, and perform therapeutic and diagnostic procedures. Examples include but are not limited to IV fluids, medications, dressing supplies, endotracheal tubes, hemodialysis circuit, towels and linens (Marshall et al., 2017).

The ICU Team

The ICU team is "specially qualified, interdisciplinary, and interprofessional." (Marshall et al., 2017, p. 273). The basic structure of the ICU team includes specialty trained nurses and physicians; however, the majority of ICUs function with interprofessional teams including but not limited to respiratory therapists (RTs), pharmacists, physiotherapists, nutritionists, social workers, spiritual workers, personal support workers, and occupational therapists (Marshall et al., 2017; Thompson et al., 2012).

ICU nurses and physicians are essential members of the critical care team. ICU nurses are primary providers of care and ensure continuous monitoring of critically ill patients' conditions, critically examining and responding to any changes, managing and administering life-supporting treatments, and collaborating with other team members as well as the patients' family members or substitute decision makers (Marshall et al., 2017; Nates et al., 2016). While educational

requirements for ICU nurses may vary, the CACCN has identified the "ability to think critically, anticipate and recognize subtle changes, and manage complex fluctuation in a deterioration of patient's status" as fundamental and paramount to the ICU nurse (2019, p. 1). The number of nurses available in a unit varies based on patient acuity but where possible, one-to-one ratios are ideal for patients who are being mechanically ventilated (CACCN, 2019; Nates et al., 2016).

ICU physicians commonly assume the role of the most responsible practitioner (MRP). In Canada, MRP refers to the health care professional that is responsible for directing and coordinating patient care and has access to privileges such as admitting and discharging patients (Canadian Medical Protective Association, 2016). ICU physicians evaluate the patient's condition, provide guidance and direction for the management of the patient's condition, and perform lifesaving procedures and interventions (Marshall et al., 2017; Nates et al., 2016). The critical condition of ICU patients also mandates that medical staff are always available to address emergencies or possible decision-making situations (either immediately within the unit or accessible by phone). Similar to nursing staff, the number of physicians available in an ICU can vary depending on unit patient load, acuity of the patients within the unit, the time of the day, type or level of the unit, and the availability of supporting staff such as ICU fellows, residents or nurses functioning at the level of advanced practice (e.g., nurse practitioners) (Marshall et al., 2017).

RTs are also integral to the care of critically ill patients. RTs play an essential role in assessing and evaluating the patient respiratory status, managing supplemental oxygen delivery and ventilation modalities, and assisting in airway related procedures such as bronchoscopies and tracheostomies (Marshall et al., 2017; Thompson et al., 2012). Depending on the jurisdiction,

RTs may also assume the role of advanced airway management and may be responsible for intubating patients (Miller et al., 2020).

The ICU Patients

ICU patients are those who are either at risk for, or already experiencing acute life-threatening organ dysfunction or failure (CACCN, 2019; Marshall et al., 2017, Nates et al., 2016). The exact type of patient condition and volume will vary depending on the ICU specialty, level, and capacity (Fowler et al., 2015; Marshall et al., 2017; Nates et al., 2016). According to the Canadian Institute for Health Information (CIHI) (2016), eight out of 10 patients are admitted to the ICU urgently and unexpectedly, while the rest are admitted as an anticipated part of their illness/surgery course. In Canada, a cross sectional study by Fowler et al. (2015) found that the majority of ICUs (97.9%, 280/286) cared for medical, surgical, and mixed patient population. The same study also reported that some ICUs specialized in the care of medical, cardiac, or cardiothoracic surgical patients, alongside caring for other types of critically ill patients. Additionally, Fowler et al. (2015) identified two ICUs within Canada that only cared for burn patients, and three ICUs that only worked with neurological or neurosurgical patients. Further, while critically ill patients comprise the majority of the ICU patient population, it is not uncommon for ICUs to provide care for chronically ill patients experiencing an acute exacerbation of their illness (e.g., acute decompensation in heart failure) or they may require ongoing mechanical ventilation due to neurological conditions or spinal cord injuries (Marshall et al., 2017)

The ICU Practice

ICU practice encompasses all the services, measures and interventions that can be provided to a patient and family experiencing critical illness. The primary focus of the ICU is

preventing or slowing the progression of physiological deterioration and maintaining or supporting the functions of vital organ systems (Marshall et al., 2017; Nates et al., 2016). While some patients may respond to treatment and recover, others do not, and ultimately die in the ICU (see Death and Dying in the ICU for more detailed statistical information). The latter necessitates that the ICU is capable of providing quality end-of-life care for patients and their families both within and outside the context of WLSM (Marshall et al., 2017).

Classification of ICUs

In Ontario Canada, ICUs can be classified into Level One, Level Two, or Level Three ICUs. Table 2.0 provides a detailed summary of the various ICU levels. In this section a more detailed description of a Level Three unit is provided because it best describes the study setting for this research.

Level Three represents the highest level of intensive care (Marshall et al., 2017, Nates et al., 2016). These ICUs are staffed with a team of intensive care specialists, physicians training in the intensive care specialty (fellows), and medical residents from specialties such as anesthesia, emergency medicine, surgery, or medicine. Continuous coverage of a Level Three ICU is usually provided by a staff physician, a critical care trainee (fellow), or critical care trained nurse practitioner (Marshall et al., 2017). The nursing staff within Level Three ICUs has additional training in intensive care. Nurse to patient ratios are generally allocated based on patient condition, but often in a ratio of one nurse to two patients or less (Marshall et al., 2017; Nates et al., 2016). A Level Three ICU can provide the full range of intensive care services including invasive and noninvasive monitoring, all varieties of oxygen supplementation and mechanical ventilation, all forms of vasoactive and inotropic agents, and all forms of renal replacement therapies. Some level three ICUs might offer advanced modalities such as invasive neurological

monitoring and extracorporeal membrane oxygenation (Marshall et al., 2017). These units often have academic affiliation and serve as training sites for new ICU physicians and nurses (Marshall et al., 2017).

Table 2.1 Summary of Levels of ICU Designation (Critical Care Services Ontario, 2020).

	Level One ICU	Level Two ICU	Level Three ICU
Physicians	• Some critical care experience. • No Formal ICU training. • On site during the day. • Accessible during the night.	• Critical care experience. • Formal training in specialties such as anesthesia, emergency medicine, medicine, surgery, and/or ICU. • On site during the day. • Quickly available during nights.	• Critical care experience. • Formal training in specialties such as anesthesia, emergency medicine, medicine, surgery, and/or ICU. • Continuous coverage by an intensivist, a critical care fellow, or a critical care trained nurse practitioner.
Nurses	• Some ICU experience. • No Formal ICU training.	• Critical care experience. • Some formal ICU training and qualifications.	• Critical care experience. • Formal ICU training. • Additional ICU training and qualifications.
Nurse to Patient Ratio	One nurse to four patients or less.	One nurse to three patients or less.	One nurse to two patients or less.
Other Healthcare Professional	Accessible but not a part of the ICU team	May be a part of the ICU team	Multiple specialties are a part of the ICU team such as respiratory therapists, physiotherapists, pharmacists, and others.
Examples of Intervention provided	• Continuous non-invasive monitoring. • Administration and titration of antiarrhythmic or vasodilators.	• Continuous non-invasive and invasive monitoring. • Non-invasive ventilation, and short-term invasive ventilation.	Full range of intensive care services including: • Continuous non-invasive and invasive monitoring.

	• Delivery of supplemental oxygen. • Non-invasive ventilation, and short-term invasive ventilation	• Administration and titration of vasoactive agents. • Renal replacement therapies	• Non-invasive ventilation, and invasive ventilation. • All forms of vasoactive and inotropic agents. • All forms of renal replacement therapies • Specialty care including neurological support and/or trauma care may be available.

Life-Sustaining Measures in the ICU

In a position paper on withholding and withdrawing life-sustaining measures, the Canadian Critical Care Society (CCCS) define LSMs as "medications or medical devices (also known as life support) using mechanical or other artificial means to support or replace vital organ function on either a temporary or permanent basis" (Bandrauk et al., 2018, p. 105). A distinctive feature of LSMs is that they are *only capable of sustaining* organ functions and are incapable of restoring those functions (Bandrauk et al., 2018). While the most commonly used LSMs are MV and vasoactive medications (Epker et al., 2015), LSMs also include interventions such as artificial nutrition, renal replacement therapy, extracorporeal membrane oxygenation, ventricular assist device and others (Epker et al., 2015; Mark et al., 2015)

LSMs are not routine interventions; they require specialty trained staff, specialized resources, and purposively designed spaces that the ICU provides (Bandrauk et al., 2018; Marshall et al., 2017). The provision of those measures requires collaborative, coordinated efforts from ICU nurses, physicians, RTs, and other care providers. LSMs are typically initiated

in response to an evident or anticipated organ system failure, and they are weaned off when the organ system has recovered, or the care goals/direction of care (i.e., from a curative focus to comfort focus) change (Bandrauk et al., 2018). For example, vasoactive and inotropic drugs are generally initiated in response to a patient's blood pressure and cardiac output remaining below normal thresholds despite IV fluid resuscitation; they are gradually weaned off as the patient's cardiovascular system becomes able to sustain a blood pressure and output that is within normal thresholds without the need for vasoactive medications.

While all forms of LSMs are important to the care of ICU patients, this chapter focuses purposefully on MV. MV refers to the use of mechanically generated pressure and regulated oxygen fractions to support the patient's respiratory system (Poor, 2018). The earliest form of MV involved using negative pressures outside of the patient's chest to assist the lungs and the breathing muscles in respiration process (Potchileev et al., 2021). Those negative pressures were created using a sealed chamber or what commonly became known as the *Iron Lung* that was used for the management of patients diagnosed with polio (Potchileev et al., 2021). Today, however, MV is almost exclusively based on the use of positive pressure ventilation. In positive pressure ventilation, a variety of positive pressures are used to support the patient's lungs and breathing muscles throughout respiration. MV is indicated in cases of respiratory failure and in cases where airway protection is needed (Potchileev et al., 2021). Examples of illnesses where a patient might require respiratory support through MV include severe pneumonia, chronic obstructive pulmonary disease, and smoke inhalation injuries (Poor, 2018; Potchileev et al., 2021). Examples of instances where airway protection is required include decreased level of consciousness or trauma (Potchileev et al., 2021).

MV can be delivered non-invasively and invasively. Non-invasive ventilation is delivered using tightfitting masks that cover the patient's nose, or nose and mouth simultaneously. Examples of noninvasive ventilation include bilevel positive airway pressure ventilation (BiPAP) and continuous positive airway pressure ventilation (CPAP). Noninvasive ventilation is used as a temporary measure in instances where respiratory system failure is evident or imminent but where the failure is not severe enough to necessitate the use of intubation and subsequent invasive MV (Potchileev et al., 2021; Valiani et al. 2017).

Invasive MV entails the introduction of an endotracheal tube (intubation) through the patient's mouth or nose or a cannula through a surgical incision (e.g., tracheostomy or cricothyrotomy) and the subsequent use of a mechanical ventilator to facilitate oxygen delivery and carbon dioxide removal (Poor, 2018, Potchileev et al., 2021). Invasive MV is indicated in cases of respiratory system failure where non-invasive ventilation has been inadequate as well as cases where airway protection is required (Poor, 2018; Potchileev et al., 2021). In Canada, relatively recent data indicates that 33% (more than 65,500) of patients who were admitted to ICU between 2013 and 2014 required invasive ventilation (CIHI, 2016). At that time, data from CIHI suggested that Canadian ICUs would see an increase in the demand for mechanical ventilation of 57% by 2026 (CIHI, 2016). It is important to note the estimated increase maybe dramatically altered depending on the outcomes of the current COVID-19 pandemic.

Invasive MV entails a multitude of settings and parameters that enable ICU clinicians to fine tune respiratory support to the patient's condition (Poor, 2018). While an in-depth exploration of parameters, measurements and waveforms are beyond the scope of this review, Table 2.2 provides a summary of ventilator modes and parameters commonly used and applicable within the scope of this thesis. It is also important to note, that the use of MV is not a

straightforward process. The management of MV, particularly invasive ventilation, requires collaborative efforts between ICU nurses, physicians and RTs and a close consideration of the patient's anatomy, physiology, underlying pathophysiology as well as their response to treatments (Burns et al., 2018; Poor, 2018 Potchileev, 2021). The use of invasive MV also necessities the administration of sedative and analgesic agents to manage the discomfort and anxiety associated with receiving MV (Moreira & Serpa Neto, 2016; Patel & Kress, 2012). Further, MV may result in some patient complications such as MV associated infections, or lung injury (Haribhai & Mahboobi, 2021). The ICU team is constantly working to prevent MV related complications, as well as screen patients for those complications and promptly manage them should they arise (Haribhai & Mahboobi, 2021).

The role of clinicians with respect to the management of invasive ventilation may vary across ICUs and across care providers' scope of practice. Generally speaking, the ICU physician's role includes directing the care of the patient in terms of the initiation and withdrawal of ventilation, the insertion of endotracheal tubes and performing tracheostomies. ICU nurses, under typical situations, take on the role of continuously monitoring the patient's overall condition, titrating sedative and analgesic infusions, and responding to any changes in the patient's status, ventilator alarms, and performing endotracheal suction. ICU nurses with expanded scope of practice (e.g., Critical Care Nurse Practitioners or Acute Care Nurse Practitioners) may intubate and enact roles similar to ICU physicians (CACCN, 2011). In ICUs where RTs are a part of the team and readily available within the ICU, they take on the role of managing the mechanical ventilator, monitoring the patient's respiratory status, and as previously indicated, may have also assumed the role of intubation. RTs also have responsibilities related to the withdrawal of ventilator support including extubation (Grandhige et

al., 2016). However, in ICUs where RTs are not routinely part of the ICU team or immediately available, these tasks may be assumed by the ICU nurse or physician (Marshall et al., 2017; Thompson et al., 2012).

Table 2.2. Modes of Mechanical Ventilation (Hite, 2011)

Ventilation Mode	Brief Explanation
Assist-Control Ventilation (ACV) also known as Continuous Mandatory Ventilation (CMV)	In this mode, each breath is fully supported and controlled. A rate of breaths per minute is set and the ventilator controls the breathing pressures and volumes of air. The patient may initiate their own breath, but the ventilator retains control over pressures and volume. In this mode the patient is unable to take any truly spontaneous breaths without interference form the ventilator
Synchronized Intermittent-Mandatory Ventilation (SIMV)	This mode ensures a set minimum rate of full controlled breaths but allows the patient to take on additional partially supported breaths. In this mode, when the patient initiates a breath, the ventilator only provides partial and not full support. The ventilator synchronizes controlled breaths with those spontaneously generated ones to aid patient comfort and reduce chances of over-inflation.
Pressure Support Ventilation/Continuous Positive Inspiratory Pressure (PSV/CPAP)	This mode only provides pressures support to the patients and allows them to control the volumes and rate of their breathing.
Pressure Controlled Ventilation (PCV)	This mode is fully controlled by the ventilator. A rate, and pressures are set, and they together determine the volumes of air moved. The patient cannot initiate spontaneous breath in this mode.

Death and Dying in the ICU

According to CIHI (2016), the mortality rate for Canadian ICU patients for the year of 2013-2014 was 9%. This rate was more than double at 19% for ICU patients who were invasively ventilated compared to 4% for those who were not (CIHI, 2016). Worldwide, however, ICU mortality rates range from 6% in Germany (Kaben et al., 2008), to 10% in the United States (Wunsch et al., 2011). According to the Intensive Care National Audit and Research Centre (ICNARC), ICU mortality rate in England, Wales and Northern Ireland, was

13.9% of patient admitted to ICU during the period from April 2019 to March 2020 (ICNARC, 2020). The Society of Critical Care Medicine (SCCM) report that ICU mortality rate on average range between 10% and 29% depending on the population's age, comorbidities and severity of illness (SCCM, n.d.). As evident, mortality rates in ICUs are variably reported across the literature.

In a prospective, multicenter study conducted in France that included 96 ICUs and 698 patients, 84% of participants had failure of one or more organs at the time of death. Further, the study showed that 89% of the patients were on LSMs prior to dying in the ICU (Orban et al., 2017). MV was the most used LSM with a utilization rate of 85% (n= 593) among the 698 included in the study (Orban et al., 2017). Importantly, while some ICU patients die unexpectedly (e.g., cardiac arrest or quick decompensation), the majority die expectedly and after the decision to WLSM (Coombs et al., 2012; Mark et al., 2015; Orban et al., 2017). In the study done by Obran et al. (2017), 68% (473/698) of patients died expectedly, and 69% (326/473) of those patients died after WLSM.

In the case of expected patient death, Coombs et al. (2012) described the dying process in the ICU as one that is composed of three main stages: "admission with hope of recovery", "transitioning from intervention to end of life care" and finally, "a controlled death" (p. 522, Fig.1). During the first stage, "admission with hope of recovery", the ICU team undertakes maximal therapeutic efforts while working to assert the patient's desired quality of life and the types of invasive measures that could be used that are consistent with their wishes (Bach et al., 2009; Coombs et al., 2012; Ranse et al., 2016). While it is ideal that those conversations are done with the patient prior to them undergoing any LSM, it is not uncommon that the patients' substitute decision maker(s) have these conversations with the ICU team due to the patient's

deteriorating or compromised state (Bach et al., 2009; Coombs et al., 2012). The latter becomes more common with the introduction of invasive ventilation because it is accompanied by the use of continuous sedative and analgesic agents, typically rendering the ICU patient unable to speak and often in a state of reduced consciousness. This is further complicated by the fact that Advance Care Directives (ACD) are often not completed or even discussed prior to ICU admissions. For example, in a study done in the United States by Rao et al. (2014), only 26.3% of the 7946 public respondents had completed ACD. Within the context of the ICU, another study done in the United States reported that less than half (42.4%) of the 450 older adults (over 65 years) included in the study had completed ACD upon admission (Gamertsfelder et al., 2016). Accordingly, those initial conversations regarding LSMs and goals of care are crucial and serve as a baseline for initial decision making as well as for future decision-making during an admission should a patient's condition continue to deteriorate and death is imminent (Coombs et al., 2012).

If the patient continues to deteriorate despite the use of maximal therapeutic efforts *or* becomes unable to live without LSMs, the ICU team initiates a transition from intervention-oriented care to comfort and end-of-life care (Coombs et al., 2012; Ranse et al., 2016). The decision to shift the focus of care is a collaborative effort between the ICU team, the patient (if possible) and their family or SDM. The ICU team holds meetings with the patient (again, if possible) and their family and discuss the course of the illness in the ICU and present the patient's diminishing prognosis and suggest a change of focus – from curative to comfort. Once the patient and/or their family are ready to transition toward end-of-life care, the ICU team then discusses the patient's wishes for a good death and presents the strategies that will be in place to

minimize any distress during the dying process and facilitate a controlled death (Coombs et al., 2012).

Other members of the ICU interdisciplinary team, including social work and spiritual care, for example, are consulted and integrated in the care of the patient and family. These providers help support the patient and family as they process and work through the transition to end-of-life care – they play an important role in grief and bereavement support (Ranse et al., 2016). While all members of the ICU team play important and essential roles in caring for dying patients their families, ICU nurses have a primary role because they are continuously present at the bedside (Adams et al., 2011; Ranse et al., 2016).

End-of-Life Care and the WLSM in the ICU

Once all the patient's and/or family/SDM's questions and concerns have been answered and addressed, the ICU team moves forward with the initiation of the third stage which entails providing palliative and end-of-life care to facilitate the WLSM and allow a controlled patient death (Coombs et al., 2012). During this final stage, the ICU team co-creates a care plan that is aimed at alleviating suffering and ensuring comfort for the patient (Mark et al., 2015; Wiegand, 2014; Wiegand et al., 2018), as well as supporting the patient's family as they process their grief and spend their last moments with their loved ones (Coombs et al., 2012; Ranse et al., 2016; Robert et al., 2017). While specific practices may vary across nations, regions, ICUs, and clinicians (Mark et al., 2015), core elements of end-of-life care in the ICU are the anticipation and prevention of patient distress as well as timely management of distress should it still arise despite anticipatory and preventative measures (Kompanje et al., 2008; Ranse et al., 2016; Stokes et al., 2019; Vanderspank-Wright et al., 2011; Wiegand et al., 2019).

The process of WLSM and dying, may be accompanied by pain, restlessness, and distress for patients (Kompanje et al., 2008; Laserna et al., 2020; Robert et al., 2017; Wiegand et al., 2018). In anticipation of those symptoms, the ICU team will often use a combination of pharmacological approaches including but not limited to sedatives, analgesics, anxiolytics, and symptom specific measures (e.g., anticholinergics for secretion management) to either prevent or alleviate distress associated with the WLSM (Epker et al., 2011; Laserna et al., 2020). In a systematic review and meta-analysis, Laserna et al. (2020) reported that morphine was the most commonly used opioid with a utilization rate of 60% (95% CI 48-71%), while midazolam was the most commonly used sedative anxiolytic agent with a utilization rate of 28% (95% CI 23-32%). Further, the same study reported that doses of opioids and sedative medications increased as the process of end-of-life care was unfolding (Laserna et al., 2020). While all members of the ICU team play a role in end-of-life care and the WLSM, again, ICU nurses assume a primary role with respect to both the delivery of end-of-life care and the WLSM (Adams et al., 2011; Robert et al., 2017; CACCN, 2017). The role of the ICU nurse in care at the end-of-life for critically ill patients includes the initiation and titration of the prescribed analgesics and sedatives, the weaning of vasoactive medications, the weaning of ventilatory support (if no RTs are present), monitoring patients for signs and symptoms of distress, responding appropriately to distress, supporting the patient's family and facilitating their grief and bereavement experience, communicating and coordinating with the ICU care team throughout this process as well as frequently engaging in acts of care that promote meaningful experiences for family members (CACCN, 2017; Ranse et al., 2016; Stokes et al., 2019).

Once all anticipatory and preventative measures are established and all family members (those who want or are able to be present) are at the bedside, the ICU team, led by the ICU nurse,

begin the process of WLSM (Epker et al., 2011; Laserna et al., 2020; Sprung et al., 2003); the patient dies subsequent to the WLSM (Bach et al., 2009; Coombs et al., 2012). Currently, there are global, national, regional, institutional, and individual variations evident in the approach to WLSM (Efstathiou et al., 2020; Mark et al., 2015). However, the process generally entails a gradual stepwise or one-step reduction of the support being delivered to the patient's failing organ systems, including ventilatory support (Mark et al., 2015).

According to Orban et al. (2017), over half of patients who had died in the ICU underwent WLSM. A range of 45% to 76% of ICU patients undergoing WLSM died within 60 minutes from the initiation of withdrawing support (De Groot et al., 2012; DeVita et al., 2008; Rabinstein et al., 2012; Wind et al., 2012; Yee et al., 2010). Cooke et al. (2010) reported that more than half of the ICU patients who underwent WLSM died within 24 hours after the withdrawal. In a study done by Gerstel et al. (2008), the process of withdrawing life support took more than a day for over half of the patient who died in ICU. Time to death from WLSM periods greater than 24 hours were associated with patients who were young, had a longer ICU stay, were on multiple life-sustaining therapies, had lower incidence of cancer, or had multiple substitute decision makers involved (Gerstel et al., 2008).

Dean et al. (2010) reported that cardiovascular support and renal replacement therapies were the life-sustaining measures most commonly withdrawn. In a modified Delphi study by Downar et al. (2016), the recommendation was made that each ICU develops its own protocol for WLSM based on its patient population and practice. Downar et al. (2016) also suggested that such protocols be modified to accommodate the individual patient's and family's needs and underlying medical conditions. Downar et al (2016) also recommended withdrawing vasoactive agents, mechanical ventilation, and artificial airway in that order *and* in steps (Downar, 2016).

This is supported by the study done by Gerstel et al. (2008) that concluded that a staggered approach to WLSM was associated with higher family satisfaction.

Withdrawal of Invasive Mechanical Ventilation

The withdrawal of invasive MV is a highly discussed and debated area of the WLSM (Efstathiou et al., 2020). In a Dutch study conducted by Epker et al. (2015) in two ICUs, 93% of the patients included in their study underwent withdrawal of invasive ventilation during the WLSM. In a multicenter French study by Robert et al. (2017), over 27% of patients who received invasive mechanical ventilation ended up having it withdrawn. In a systematic review, Efstathiou et al. (2020) reported that the average median time from ventilation withdrawal to patient death was 61.7 minutes. Efstathiou et al. (2020) also reported that "being male, of non-white race, having co-morbidities and increased respiratory support" (p. 1153) were factors associated with having a shorter period to death after the withdrawal of mechanical ventilation.

The withdrawal of MV and artificial airway support is associated with significant changes to the patient's physiology and often produces signs and symptoms of respiratory distress, increased respiratory secretions, airway obstruction, and discomfort (Kompanje et al., 2008; Laserna et al., 2020; Robert et al., 2020). In a study done by Robert et al. (2020) that included 450 patients who underwent the withdrawal of MV in the ICU, 50% (n=225) experienced discomfort. Patients who displayed signs of discomfort, in general, received less midazolam, similar doses of morphine, and were less sedated overall compared to those who did not show any signs of discomfort. Being deeply sedated and receiving vasoactive medications were the only two factors to be reported as independently associated with not experiencing discomfort (Robert et al., 2020).

In their modified Delphi study, Downar et al. (2016), recommended that the process of MV withdrawal be individualized for each patient with comfort as a focus and that invasive ventilation be withdrawn "as quickly as comfort allows" (p.1012). However, when it comes to the actual process of withdrawing invasive MV, there exists a variation across the literature regarding the best practices in WLSM (Efstathiou et al., 2020). According to the literature, there are two methods that are commonly used to discontinue invasive MV during the process of WLSM. The first process is known as TW and involves gradual, stepwise reductions in ventilatory support until the patient is transitioned to t-piece (maintains the ETT in place but allows for the discontinuation of mechanical ventilator) or is extubated to room air. The other method is known as TE and entails the cessation of ventilatory support and removal of artificial airway in one step (Efstathiou et al., 2020; Robert et al., 2017).

Globally, countries vary in their choice of methods and process to withdraw invasive ventilation, and in some instances, evidence is lacking on the topic because the WLSM is considered illegal (Efstathiou et al., 2020). As previously mentioned, (see Chapter 1), while the guidelines published by Downer (2016) recommended that invasive MV be withdrawn "as quickly as comfort allows" (p. 1012), they did not provide any insight or guidance specific to which of the two methods (TW or TE) is preferable. In the remainder of this chapter, I will compare and contrast TW and TE and consider the impact they have on the patient and the experiences of family members, as well as the practices and preferences of ICU clinicians within the context of care at the end-of-life in the ICU

The Impact of Terminal Weaning and Terminal Extubation on Patients and Families

Three main areas of the impact of TW and TE on the patient have been explored in the literature. Those areas are signs of respiratory discomfort during and after withdrawal of MV,

time to death after MV withdrawal, and sedation and analgesia administered to the patients as a part of the withdrawal process (Campbell et al., 2015; Robert et al., 2017; Thellier et al., 2017). Each area of impact is discussed separately.

Signs of Respiratory Discomfort

A study across 43 French ICUs done by Robert et al. (2017) compared a group of patients who underwent TW (n=248) to a group that underwent TE (n=210). The findings revealed that TE was associated with higher incidences of: 1) airway obstruction (65.7% for TE versus 51.6% for TW ($p=0.002$)); and 2) gasping (44.8% for TE versus 20.2% for TW ($p<0.001$)). Further, a pilot study by Campbell et al. (2015) compared patients who underwent TW (n=5) over a period of 18 minutes on average to those who underwent TE (n=8) in one-step under one minute. Campbell et al. (2015) concluded that patients who underwent TW on average had lower respiratory distress observation scores compared to those who had MV withdrawn using TE.

Time to Death after MV Withdrawal

Two studies reported on the time from MV withdrawal to patient death. Thellier et al. (2017) explored TE and TW in regard to the duration from MV withdrawal completion to patient death. In their study, TE was performed for patients (n=22) who were not on any vasoactive drugs, had an arterial blood oxygen saturation (SaO_2) of greater than 95%, required less than 50% fraction of inspired oxygen (FiO_2), and less than 5 cm H_2O of PEEP. TW was performed for patients (n=46) who did not meet the TE criteria. Patients who underwent TW had an average time to death of two hours while those who underwent TE had an average of 32 minutes ($p<0.001$). Further, 32% of the patients who underwent TW died within one hour from completion of the withdrawal of MV, while 68.2 % of those who underwent TE died within one hour from TE ($p<0.005$).

Robert et al. (2017) compared the period from the start of MV withdrawal between the TE and TW group in their study. Patients who underwent TE died after a median of 2.7 hours (Interquartile Range [IQR]: 0.4-10.9 hours) after extubation, while patients who underwent TW died after a median of 3.9 hours (IQR: 1.0-17.8 hours). In both studies, Thellier et al. (2017), and Robert et al. (2017), patients who underwent TE died earlier than those who underwent TW.

Sedation and Analgesia Administered During Withdrawal of MV

Few studies reported on sedation and analgesia administration during the withdrawal of MV. Campbell et al. (2015) reported that patients who underwent TW received higher doses of morphine while those who underwent TE received higher doses of midazolam. Further, Thellier et al. (2017) reported that patients who underwent TW received higher doses of midazolam and sufentanil compared to those who underwent TE; however, this was not a statistically significant finding.

The Impact on Families

Few studies explored the impact of the MV withdrawal method on the patient's family. Thellier et al. (2017) reported that TE was associated with 100% (22/22) family presence versus 84.8% (39/46) for TW. Robert et al. (2017) used the Impact of Events Scale-Revised to assess for post-traumatic stress disorder (PTSD) related symptoms 3 months after patient death, Hospital Anxiety and Depression Scale at 3, 6, 12 months, and the Inventory of Complicated Grief at 6 and 12 months from patient death. The study found no significant difference between the TE and TW groups. Kross et al. (2011) reported that family members of patients who died after being extubated and those of patients who died with the tube in-situ, both had low incidence of PTSD using the PTSD Checklist Civilian Version.

Gerstel et al. (2008) used the Family Satisfaction in the ICU scale to examine satisfaction levels in 584 family members of patients who underwent WLSM and died in the ICU. The study showed that longer periods of withdrawal and having the patient extubated before death were associated with higher family satisfaction. Gerstel et al. (2008) concluded that a slow staggered approach to WLSM was likely associated with higher family satisfaction as it gave the family more time to grieve and process the patient's death.

Clinicians Practices and Preferences

The frequency of utilization of TE and TW varies globally (Efstathiou et al., 2020). For example, in Canada, one analysis of 35 patients reported that 75% of patients were extubated during the process of MV withdrawal (van Beinum et al., 2016). In the United States, for comparison, Gerstel et al. (2008) reported that 83% of a total of 431 patients were extubated during the process of MV withdrawal. In France, a survey of 451 ICU clinicians reported that TW was performed more than twice as much as TE (46.3% vs 19.5%) (Cottereau et al., 2016) while another reported a higher rate of TE (32.5%) in the French context (Thellier et al., 2017).

Cottereau et al. (2016) explicitly compared ICU physicians' and nurses' practices and preference regarding TW and TE. They surveyed n = 225 ICU nurses and n = 226 ICU physicians across 46 ICUs in France regarding their perceptions and preferences between TE and TW. They reported that only 11.9% of the nurses and 5% of the physicians have never, or almost never, performed TW. In contrast, 43.4% of nurses and 19.4% physicians have never, or almost never, performed TE. The study also showed that 21.2 % of the participants preferred TW over TE, 18.1% preferred TE over TW, while the majority of participants indicated having no preference between the two. Participants who preferred TW believed that TE was "*distressing for the family*" (81.5%), "*a form of Euthanasia*" (65.4%), "*does not give the patient a chance for*

survival" (77.8%), "*causes the patient to suffocate*" (65.4%), and "*causes conflict among staff*" (53.15%). The same group believed that TW was "*more comfortable for the patient*", "*better accepted by nurses*" (98.8%) and "*physicians*" (87.7%), "*allows time for titrating analgesia and sedation*" (93.8%), and "*gives the patient a chance for survival*" (14.8%) (p.1254). On the other hand, participants who preferred TE believed that TE was "*was more comfortable for the patient"* (73.9%), *"better accepted by nurses"* (69.6%) and "*physicians"* (78.3%), "*made death more natural and less medical"* (95.7%), *"did not delay death"* (94.2%), *"eliminates ambiguity and false hope"* (94.2%), and *"restores the patient natural appearance"* (100%). This group also believed that TW *"prolonged the dying process"* (68.1%), *"gave family false hope"* (50.7%), and *"causes patient discomfort"* (34.8%) (p. 1254). The study also reported that 64% (n = 142/225) of the nurses and 28% (n = 63/226) of the physicians felt a moral difference between TE and TW and that clinicians who preferred TE and those who did not have a preference both viewed TE as a more natural way of dying with less ambiguity.

Grandhige et al. (2016) explored the attitudes and experience of sixty-one respiratory therapists (RTs) regarding TE and end-of-life care. Grandhige et al. (2016) reported that 70% of the participating RTs felt comfortable with the decision to terminally extubate a patient; 72% of the RTs felt comfortable terminally extubating the patient themselves: 50.8% of the RTs were comfortable with the family being present during and after TE; and 14.8% of the RTs preferred that TE is carried out by the physician. Further, 39.3% of the RTs in their study reported that they were given the option not to perform TE if they felt uncomfortable with it due to moral or ethical concerns. Additionally, 26.2% of RTs reported that the physicians were present at the bedside during TE, and only 1.6% of the RTs reported that TE was carried out by the physician. Further, Grandhige et al. (2016) reported that while 47.5% of the RTs in their study would have

liked to be included in the family meeting to discuss MV withdrawal, only 6.6% of the RTs were involved in those meetings. Finally, Grandhige et al. (2016) reported that 67.2% of the RTs in their study felt that the ICU team communicated with them directly regarding the TE process when it was chosen for MV withdrawal.

Specific to nurses and physicians, Robert et al. (2017) compared Job Strain Scores (JSS) in relation to TE and TW among ICU nurses, nursing assistants, senior physicians, and resident physicians. Their analysis found no significant differences between the groups across the total scores of the JSS. However, when examining the components of the JSS, they reported that TW carried a higher demand for nurses compared to TE. Robert et al. (2017) also reported that TE made for higher control and stronger social support for nursing assistants and senior and resident physicians than TW, and that TE was associated with lower satisfaction with end-of-life care among resident physicians compared to TW. Accordingly, Robert et al. (2017) found TE to be better for the psychological welfare of the ICU clinicians. However, it is important to note that Robert et al. (2017) did not report on what each of the JSS domains reflected in terms of concrete descriptions or examples and consequently limited the relevance of those secondary findings.

Summary

The state of the current literature makes evident the contextual nature and the variability of end-of-life care and WLSM practices, in particular, the process of MV withdrawal in the ICU. The complexity of MV withdrawal is a key consideration for this variability and lack of clarity (Efstathiou et al., 2020). Accordingly, the purpose of this study, is to use descriptive statistics to follow the process of invasive MV withdrawal during the WLSM. In doing so, the aim is to statistically capture and describe the processes of invasive MV withdrawal and how the processes of TW and TE are undertaken during WLSM within the context of end-of-life care in

the ICU. The value of such description lies in that it helps better understand the clinical execution of invasive MV withdrawal methods and informs clinical practice.

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Chapter 3: Methods

This chapter provides an overview of the primary study as well as the design, settings, extant unit, sample, data collection and data analysis methods. Ethical considerations are also discussed.

Description of the Primary Study

This thesis is based on a secondary analysis of data collected for a larger, multi-method research study titled "Terminal Weaning and Terminal Extubation within the Context of End-of-Life Care in the ICU: Current State and Clinician Experiences" (herein referred to as the primary study). The following is a brief description of the primary study's aim, purpose and objectives.

Aim

This research study aimed to explore, in greater depth, health professionals' experiences related to the practice of terminal weaning and terminal extubation within the context of end-of-life care in the ICU.

Purpose

The purpose of the primary study was twofold: 1) to capture a current state of withdrawal practices specific to mechanical ventilation within the context of end-of-life care in the ICUs of an identified study site; and, 2) to explore ICU clinicians' (nurses, physicians and respiratory therapists) experiences of terminal weaning and terminal extubation within the context of end-of-life care, in order to better understand the process of terminal weaning and/or terminal extubation, ICU clinicians' experiences about the process, the process of decision making, how these decisions are communicated between staff members and the patients' relatives, the impact it has on professionals, patients and their relatives, and finally what support is required for all involved.

Objectives

The objectives of the primary study were to:

1. Develop, pilot test, and use an extraction tool to conduct a chart audit;
2. Develop an interview guide based on expert opinion and findings from the literature;
3. Interview ICU nurses, physicians and respiratory therapists who have been involved in terminal weaning and/or terminal extubation within the context of end-of-life care;
4. Describe the processes, identify factors that influence decision making, explore perceptions among those involved in the process, and identify what support (i.e. educational, organizational, emotional) is required by clinicians to provide high quality respiratory support at the end-of-life within the context of terminal weaning and extubation.

The secondary data analysis for this current thesis aligns with data collected as part of Objective 1 of the primary study.

Thesis Study Design

The study design was a secondary data analysis using data collected from the longitudinal retrospective chart audit from the primary study. The use of patients' charts allowed for the collection of rich, detailed data from a patient's admission to the ICU until the time of their death. The design was also retrospective in that all data collection was carried out after patients underwent WLSM and died. This design was selected because it enabled an examination of WLSM processes that were carried out over time and to establish sequences for those processes (Polit & Beck, 2017).

This study was carried out within the post-positivist world view which views reality as shared, observable, and measurable (Guba & Lincoln, 2005). Accordingly, the objectives of this

thesis project can be met by observation and measurement within our sample using various descriptive statistics; these descriptions may be both relevant and replicable in other similar contexts. The use of a longitudinal retrospective design is consistent with a post-positivist world view (Polit & Beck, 2017).

Study Setting

The study took place in two Level 3 medical-surgical ICUs at a large academic health sciences centre in Ontario, Canada. These ICUs are situated within a catchment area of approximately 1.3 million people. At the time of data collection, there was a total of 56 beds (28 beds in each unit) (personal communication, S. Larochelle). The ICU patient populations differ; Site A, provides thoracic surgery and sees a higher volume of oncology related admissions (including bone and hematopoietic stem cell transplantation) as compared to Site B which is the designated regional trauma center and houses both the vascular and neurosurgical programs (personal communication, S. Larochelle). There were approximately 400 ICU nurses across both sites and a team of 21 intensivists (ICU physicians). RTs also provided direct patient care in both units and are available 24 hours per day. Given that RTs are not designated specifically to the ICU but rotate in and out of the unit, it was difficult to provide a total number of RTs in the ICU (personal communication, S. Larochelle).

Extant Unit Practices

At the time of data collection, both sites used a corporate, pre-printed order set for the WLSM. The Comfort Care Orders protocol is a 13-item list that is often completed and signed once the decision for WLSM has been made by the healthcare team (completed and signed by an ICU physician) in collaboration with the patient (if possible) and/or their SDM. This list includes interventions aimed at maximizing comfort, minimizing distress, encouraging family presence,

and supporting the patient and their family (personal communication, S. Larochelle). Historically, the Comfort Care Orders were used predominately at Site A; in recent years, the Comfort Care Orders were also incorporated at Site B (personal communication, B. Vanderspank-Wright). The redacted Comfort Care Orders have been included for reference in Appendix A. Figure 3.1 represents the portion of the order set that is specific to the withdrawal of ventilatory support.

Figure 3.1: Ventilation Withdrawal in the Comfort Care Orders

1. Titrate to comfort:
    a. Morphine [typically changed to Hydromorphone]: start at present rate or at (generally 0.2 mg/hr), bolus (generally 0.4 mg prn), and adjust infusion prn.
    b. Midazolam: start at present rate or at (generally 2 mg/hr), bolus (generally 2-4 mg prn), and adjust infusion prn.
    c. No dosage limits: increase rate at any signs of distress:
        i. Grimacing, clutching, gasping, restlessness, diaphoresis
        ii. Respiratory rate > 24b/min, nasal flaring, accessory muscle use
        iii. Heart rate increase > 20%, SBP > 20%

10. Wean down FiO2 to 0.21, PEEP to 10 cm H2O, PS 10 cm H2O, Mode to CPAP from existing mode of ventilation.
    d. Make changes q 5-10 mins and observe patient for any signs of distress:
        i. Grimacing, clutching, gasping, restlessness, diaphoresis
        ii. Respiratory rate > 24b/min, nasal flaring, accessory muscle use
        iii. Heart rate increase > 20%, SBP > 20%
    e. If distress apparent:
        i. Increase sedatives
        ii. Increase ventilation until sedatives are effective
        iii. Scopolamine 0.3-0.6 mg IM SC, q6h PRN for secretions
    f. If no distress is apparent
        i. Do not increase sedatives, proceed to 5/5[PEEP=5, PS=5] trail, trail 5/5 trail for 10 mins
        ii. If satisfactory, extubate +/- oral airway prn, unless family or caregivers believe patient would be less comfortable (use T piece instead of extubation)
        iii. In unsatisfactory, increase sedation and try again)

FiO2: Fraction of Inspired Oxygen. PEEP: Positive End Expiratory Pressure, PS: Pressure Support. CPAP: Continuous Positive Airway Pressure. SBP: Systolic Blood Pressure. IM: Intramuscular. PRN: As needed.

Sample

Patient charts from 2017 were chosen for the chart audit in the primary study for several reasons. First, in 2017, paper-based charting was available at both sites. In 2018, the organization had begun to transition towards an electronic health record that was fully implemented in 2019. As a result, 2017 provided a snapshot whereby practices at both sites were static.

Data from the Department of Critical Care Annual Report for 2017 indicated that there was a total of 497 deaths across both sites; Site A had 246 deaths and Site B had 251. For the purpose of the primary study, 70 deceased patients' charts per site, were randomly selected using Kutool™ add-on tool for Microsoft Excel®. This add-on allows for random selection of a set number of cells in a column or row. The tool was used to randomly select 140 participants IDs to include in the primary study. The decision to randomly select charts provided an opportunity to capture variability in the sample (e.g., variability in practice, cases of neurological determination of death, cardiocirculatory death, deaths within the context of organ donation and tissue donation and those that are representative of the patient populations across both ICUs).

For this thesis study, inclusion criteria were set in an effort to identify pertinent charts from the primary study. The inclusion criteria stipulated that only those patients who had received invasive mechanical ventilation, defined herein as endotracheal intubation with subsequent mechanical ventilation, would be included. The rationale for this decision was to be able to report specifically on TW and TE practices that directly involved concurrent withdrawal of mechanical ventilation with the possibility of extubation. The application of this criterion resulted in a sample of 78 charts across the study sites. This inclusion of data extracted from these charts enabled me to satisfy thesis Objective 1: to describe the processes of terminal weaning and terminal extubation within the context of invasive ventilation. Further, because the sample included charts from both Site A and Site B, I could also satisfy thesis Objective 2: to compare, where possible, the similarities and differences in processes and practices across sites.

Data Collection

Data Collection Tool

A data extraction tool for the chart audit was developed for the primary study by the student and the thesis supervisor/principal investigator (see Appendix B). There were 17 sections included in the tool which was designed to capture the dying process in the intensive care unit from a patient's admission to the ICU until time of death. The tool was developed based on the ICU nursing flow sheet used by the nurses across both sites to document their care. The rationale for developing the extraction tool primarily from the nursing flow sheet was that the flow sheet provided a detailed, time-stamped account of all patient level interventions. For example, all ventilatory changes were documented on the nursing flow sheet, as were all comfort-oriented interventions both pharmacologic (e.g., sedation, analgesia, adjuvant medications) and non-pharmacologic (e.g., patient repositioning, suctioning, mouth care). The other nursing related document that informed the development of the extraction tool was the nursing Kardex which prompted the need for key demographic data (e.g., patient age, sex, reason(s) for ICU admission).

The first Sections, 1-5, of the data extraction tool contained demographic and admission related data, such as patient age, sex, reason(s) for ICU admission, past medical history, current admission issues, level of care upon admission to ICU (i.e., Category Status), and time and cause of death. Sections 6-9 captured the process of transitioning from a curative focus toward end-of-life care. The type of data that was extracted included when the level of care was modified, when comfort care was discussed, ordered, and initiated, as well as family presence and involvement in the WLSM process. Next, Sections 10-13 were designed to capture the patient's respiratory support and mechanical ventilation status prior to the WLSM. The last 4 Sections, 14-17,

captured data regarding the use of sedation, analgesia, and any other medications used throughout the process of WLSM and up until the time of patient death. Also captured were other medications/infusions (e.g., vasoactive medications) and how they were withdrawn.

The tool was piloted with 21 charts randomly chosen using Kutool® between the two study sites that met the inclusion criteria (at this phase, this constituted a patient death only). The piloting phase was iterative; the tool and the results of the data extraction from the charts were regularly reviewed by the student and thesis supervisor/principal investigator. As such, the tool continued to evolve and be refined until a chart could be fully extracted with ease and with consistency across charts. Once satisfied with the comprehensiveness and congruence of the data collected to answer the study objectives, the student moved on to carry out the data collection process for the full sample (n=140; 70 per site). Charts used during the pilot were not included in the full sample.

Data Collection Process

Data was collected between May and September of 2019. A master list containing patient's medical record numbers and basic demographics was provided to the student by the Clinical Care Manager of each unit. Once received, the lists were immediately protected with an 18 characters password and stored on the participating institution's secure Microsoft SharePoint© server. All charts were assigned a three letter ID and an 8-character password. Kutool™ add-on for Microsoft Excel® was used to randomly select 110 charts from each site. Data collection was carried out until a total of 70 charts were extracted per site. Cases where patients died unexpectedly (because this did not reflect a weaning or extubation process) and incomplete charts were excluded during this phase. Once the student completed data extraction from the charts, the data was then entered in a Microsoft Excel® database by two RAs (I.B. and

T.T.). Each RA was provided with an orientation to the project and data extraction tool to ensure they had a good understanding of the form. Each of the RAs was assigned an equal number of charts to enter, and they were also asked to review the charts entered by the other RA. The latter was used to maintain reliability in the data entry process and to reduce entry errors thereby ensuring congruence in the entry process. Once all the data was entered into the Microsoft Excel® database, the student (MA) reviewed all entries and randomly selected 10 participants from each site to compare the extraction forms to the data entered into the database; no errors were identified. Next, the process of coding the data was commenced. All text-based variables were coded into numerical values to allow for statistical representation and analysis. For example, a coding guide containing 47 options was created for the variable of immediate cause of death to transform text entry to numerical values. The entire dataset was then migrated to IBM Version 25 SPSS® for statistical analysis.

Data Analysis

Descriptive statistical analysis was completed. Descriptive statistics were chosen as they allowed the student to answer the research objectives and to demonstrate the process of MV withdrawal during WLSM. Variables were clustered into tables that aim to address the research objectives and will be discussed as such in this thesis. Frequency tables were created for nominal level variables and descriptive statistics such as mean, standard deviation (SD), median, minimum, and maximum were calculated for ordinal, ratio, and interval level variables (Polit, 2010). Our rationale for choosing these statistical analyses was twofold. First, most available literature on the topic of TE and TW have reported either the mean and SD, or the median and interquartile range (IQR) as evident in the systematic review done by Efstathiou et al. (2020). To compare our findings to the literature, it was decided to include all those measurements, except

IQR was replaced with minimum and maximum as the latter statistics consider outliers within the data unlike IQR. The inseparability of outliers from the sample is an important point that will be further discussed in Chapter 5. Second, being a purely descriptive study, our purpose is to provide the readers with statistics that help them visualise how the data was distributed. The minimum and maximum represent the end points of our data, while the median represent the point at which the sample is split into two halves. The mean and SD serve to illustrate how the data was influenced by the outliers.

Ethical Considerations

As this study falls under the scope of the primary, a separate ethical approval was not required. The larger research project was approved by the Research Ethic Board (REB) of the University of Ottawa, as well as the REB of the participating acute care institution. Once the project was approved, the research team was granted access to the medical charts for the patients who died in the ICU during 2017. Informed consent was not required as the data collected was a part of current practice and the project did not include any interventions. Delegation forms were created for all RAs involved in the project.

Confidentiality and anonymity were maintained using a number of strategies throughout the study. First, each patient was assigned a randomly generated three letter study identifier (ID); this study ID was the only identifier used on the data extraction form. Each completed form was then password protected as soon as it was created using a randomly generated 8-character password that contained numbers, capital case letters, and small case letters. Next, a password of 18 characters was used to safeguard the master list of those IDs and password; this master list is only accessible by the student and thesis supervisor. All files were stored on the participating

institution's secure Microsoft SharePoint © server which can only be accessed by the student and thesis supervisor/principal investigator.

Another ethical consideration to this project is the fact that the student is also a registered nurse who works primarily at Site A, but occasionally is assigned to Site B. Accordingly, any patient charts in which the student was involved as a nurse at the bedside were then reviewed by the principal investigator/thesis supervisor (BV) to ensure accuracy and objectivity of data extraction. There were two charts that met those criteria.

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Chapter 4

Terminal Weaning and Terminal Extubation Practices at the End-of-Life: A Quantitative Descriptive Analysis of Intensive Care Practices

This chapter is an unpublished manuscript prepared for submission to Nursing in Critical Care.

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Abstract

Background: The method by which invasive mechanical ventilation (MV) is removed during the withdrawal of life-sustaining measures (WLSM) remains an ongoing topic for discussion and research. Two methods are currently described in the literature: Terminal Weaning (TW) and Terminal Extubation (TE). While multiple studies have examined and compared the two methods, no research has been conducted to describe how those methods are undertaken in the clinical practice of the intensive care unit (ICU).

Aim: To statistically describe and compare the processes of TW and TE as undertaken in two Level 3 medical-surgical ICUs within one Canadian hospital.

Study Design: A secondary data analysis using data from a longitudinal retrospective chart audit from.

Results: MV was withdrawn in 88.5% of patients undergoing WLSM. TW was used in 62.3% of the cases while TE was used in 37.7%. When comparing TW to TE, patients who underwent TW were on average younger, had a longer ICU stay, higher respiratory support requirements, a longer duration of invasive MV, shorter period from first change of MV parameters to patient death, and similar rates of respiratory distress and airway obstruction after extubation. In the sample, the TW process lasted an average of one hour and thirty-two minutes and resulted in termination of MV in 62.8% of the cases, and in extubation in 53.5% of the patients.

Conclusion: This study highlights the nuances within MV withdrawal during end of life in the ICU in two ICUs within a tertiary care hospital. All ICU clinicians, particularly those who carry out the processes of WLSM, should be familiar with the various methods of WLSM, their application and how those methods impact the patients and their families. Further research is

needed to compare the methods of WLSM, particularly, the methods of MV withdrawal and examine the advantages of one approach over the other.

Keywords: Withdrawal of Life-Sustaining Measures, Mechanical Ventilation, Terminal Weaning, Terminal Extubation, Intensive Care Unit.

Introduction

Mechanical ventilation (MV) is a commonly used life-sustaining measure (LSM) in critical care for patients at risk of or experiencing respiratory failure, airway compromise and lung injury (1). MV uses positive pressure ventilation which entails using specialized equipment (i.e., mechanical ventilators) to push a mixture of gases into the patient's lungs through an artificial airway (e.g., tracheostomy or endotracheal tube [ETT]) (1). Despite best efforts, some patients who receive MV in ICUs do not recover and goals of care shift from a curative focus to comfort care anddeath (2). Because of the use of LSMs like MV, dying in the ICU often follows a shared decision-making process whereby informed decisions are made between substitute decision makers and the health care team to discontinue and subsequently withdraw the use of LSMs, including MV (3-6). The withdrawal of MV within the context of end-of-life care in the ICU is the focus of this manuscript.

Background

Withdrawal of Invasive Mechanical Ventilation

In 2016, Downar and colleagues published guidelines specific to the withdrawal of life-sustaining measures (WLSM) (7). They recommended that the process of MV withdrawal be individualized for each patient with comfort as a focus and that invasive ventilation be withdrawn "as quickly as comfort allows" (p.1012). However, when considering the practical elements of withdrawing invasive MV, there exists a variation across the literature regarding the best practices in withdrawing this life-sustaining therapy (8). For example, in a Dutch study conducted by Epker et al. (9) in two ICUs, 93% of the patients in their study underwent withdrawal of MV during the WLSM. In contrast, a multicenter French study by Robert et al. (10) reported that only 27% of patients who received MV ended up having it withdrawn. In a

systematic review, Efstathiou et al. (8) reported that the average median time from ventilation withdrawal to patient death was 61.7 minutes. Efstathiou et al. (8) also added that "being male, of non-white race, having co-morbidities and increased respiratory support" (p. 1153) were factors associated with having a shorter period to death after the withdrawal of MV.

The withdrawal of MV with concurrent removal of an artificial airway is associated with significant changes to the patient's physiology and often produces signs and symptoms of respiratory distress such as increased work of breathing, increased respiratory secretions, potential airway obstruction, and discomfort (11-13). In a study done by Robert et al. (13) that included 450 patients who underwent the withdrawal of MV in the ICU, 50% (n=225) experienced discomfort. Patients who displayed signs of discomfort were less sedated overall compared to those who did not show any signs of discomfort; they received less midazolam and similar doses of morphine. Being deeply sedated and receiving vasoactive medications were the only two factors to be reported as independently associated with not experiencing discomfort (13).

Terminal Weaning and Terminal Extubation

According to the literature, there are two methods that are commonly used to discontinue MV during the process of WLSM. The first, terminal weaning (TW), involves a gradual, stepwise reduction in ventilatory support being provided to the patient until the patient is transitioned to a t-piece (i.e., maintains the ETT in place but allows for the discontinuation of MV) or is extubated to room air (8, 10). The second method terminal extubation (TE), entails the cessation of ventilatory support and removal of artificial airway in one step (8, 10). The following sections compare and contrast these two methods of invasive MV withdrawal and consider the impact they have on the patient and the experiences of family members, as well as

the practices and preferences of ICU clinicians related to TW and TE within the context of care at the end-of-life.

The Impact of Terminal Weaning and Terminal Extubation on Patients and Families

The impact of TW and TE on the patient have been explored in the literature with a focus on: signs of respiratory discomfort during and after withdrawal of MV, time to death after MV withdrawal, and sedation and analgesia administered to the patients as a part of the WLSM process (5, 10, 14). In terms of respiratory discomfort signs, a study across 43 ICUs in France, Robert et al. (10) compared a group of patients who underwent TW (n=248) to a group that underwent TE (n=210). They found that TE was associated with higher incidences of airway obstruction (65.7% for TE versus 51.6% for TW ($p=0.002$)) and gasping (44.8% for TE versus 20.2% for TW ($p<0.001$)). Further, a pilot study by Campbell et al. (14) compared patients who underwent TW (n=5) over the period of 18 minutes on average to those who underwent TE (n=8) in one-step under one minute. Campbell et al. (14) concluded that patients who underwent TW on average had lower respiratory distress observation scores compared to those who had MV withdrawn using TE.

Two studies reported on the time from MV withdrawal to patient death. Thellier et al. (5) reported that TE was performed for patients (n=22) who were not on any vasoactive drugs, had an arterial blood oxygen saturation (SaO2) of >95%, required less than 50% fraction of inspired oxygen (FiO_2), and less than 5 centimeters of water (cm H_2O) of positive end expiratory pressure (PEEP). TW was performed for patients (n=46) who did not meet the TE criteria. Patients who underwent TW had an average time to death of two hours while those who underwent TE had an average of 32 minutes ($p <0.001$). Further, 32% of the patients who underwent TW died within one hour from completion of the withdrawal of MV, while 68.2 % of those who underwent TE

died within one hour ($p<0.005$). Robert et al. (10) compared the period from the start of MV withdrawal to time of death between the TE and TW groups. Patients who underwent TE died after a median of 2.7 hours (IQR: 0.4-10.9 hours) after extubation, while patients who underwent TW died after a median of 3.9 hours (IQR: 1.0-17.8 hours). In both studies, patients who underwent TE died within a shorter timeframe than those who underwent TW.

As for the amounts of sedation and analgesia administered during the withdrawal of MV, Campbell et al. (14) reported that patients who underwent TW received higher doses of morphine, while those who underwent TE received higher doses of midazolam. Contrarily, Thellier et al. (5) reported that patients who underwent TW received higher doses of midazolam and sufentanil compared to those who underwent TE; however, this was not a statistically significant finding in their study (midazolam $p = .39$, sufentanil $p = .75$).

Few studies explored the impact of the MV withdrawal method on the patient's family. Thellier et al. (5) reported that TE was associated with 100% (n = 22/22) family presence versus 84.8% (n = 39/46) for TW. Robert et al. (10) used the Impact of Events Scale-Revised to assess for post-traumatic stress disorder (PTSD) related symptoms three months after patient death, Hospital Anxiety and Depression Scale at three, six, and 12 months, and the Inventory of Complicated Grief at six and 12 months from patient death. The study found no significant difference between the TE and TW groups. Kross et al. (2011) reported that both family members of patients who died after being extubated and family members of patients who died with the tube in-situ, had low incidence of PTSD using the PTSD Checklist Civilian Version. Gerstel et al. (15) used the Family Satisfaction in the ICU scale to examine satisfaction levels in 584 family members of patients who underwent WLSM and died in the ICU. The study showed that longer periods of withdrawal as well as having the patient extubated before death were

associated with higher family satisfaction. Gerstel et al. (15) concluded that a slow staggered approach to WLSM was likely associated with higher family satisfaction as it gave the family more time to grieve and process the patient's death.

ICU Clinicians Practices and Preferences

The frequency of utilization of TE and TW varies globally (8). For example, in Canada, one analysis of 35 patients reported that 75% of patients were extubated during the process of MV withdrawal (16). In the United States, for comparison, Gerstel et al. (15) reported that 83% of a total of 431 patients were extubated during the process of MV withdrawal. In France, a survey of 451 ICU clinicians reported that TW was performed more than twice as much as TE (46.3% vs 19.5%) (17) while another reported a higher rate of TE (32.5%) in the French context (5). In Scotland, 571 ICU clinicians reported that TE was performed in about 23.5% of the patient cases (3).

Only one study has explicitly compared ICU physicians' and nurses' practices and preference regarding TW and TE. Cottereau et al. (17) surveyed n = 225 ICU nurses and n = 226 ICU physicians across 46 ICUs in France regarding their perceptions and preferences between TE and TW. The study found that only 11.9% of the nurses and 5% of the physicians had never, or almost never, performed TW. In contrast, 43.4% of nurses and 19.4% physicians had never, or almost never, performed TE. The study also showed that 21.2 % of the participants preferred TW over TE, 18.1% preferred TE over TW, while the majority of participants indicated having no preference between the two. Participants who preferred TW believed that TE was "*distressing for the family*" (81.5%), "*a form of Euthanasia*" (65.4%), "*does not give the patient a chance for survival*" (77.8%), "*causes the patient to suffocate*" (65.4%), and "*causes conflict among staff*" (53.15%). The same group believed that TW was "*more comfortable for the patient*", "*better*

accepted by nurses" (98.8%) and "*physicians*" (87.7%), "*allows time for titrating analgesia and sedation*" (93.8%), and "*gives the patient a chance for survival*" (14.8%) (p.1254). On the other hand, participants who preferred TE believed that TE "*was more comfortable for the patient"* (73.9%), *"better accepted by nurses"* (69.6%) and "*physicians"* (78.3%), "*made death more natural and less medical"* (95.7%), *"did not delay death"* (94.2%), *"eliminates ambiguity and false hope"* (94.2%), and *"restores the patient natural appearance"* (100%). This group also believed that TW *"prolonged the dying process"* (68.1%), *"gave family false hope"* (50.7%), and *"causes patient discomfort"* (34.8%) (p. 1254). The study also reported that 64% (n = 142/225) of the nurses and 28% (n = 63/226) of the physicians felt a moral difference between TE and TW. Clinicians who preferred TE and those who did not have a preference, both viewed TE as a more natural way of dying with less ambiguity.

Grandhige et al. (18) explored the attitudes and experience of sixty-one respiratory therapists (RTs) regarding TE and end-of-life care. Grandhige et al. (18) reported that 70% of the participating RT felt comfortable with the decision to terminally extubate a patient; 72% of the RTs felt comfortable terminally extubating the patient themselves: 50.8% of the RTs were comfortable with the family being present during and after TE; and 14.8% of the RTs preferred that TE was carried out by the physician. Additionally, 39.3% of the RTs in their study reported that they were given the option not to perform TE if they felt uncomfortable with it due to moral or ethical concerns. Additionally, 26.2% of RTs reported that the physicians were present at the bedside during TE, and only 1.6% of the RTs reported that TE was carried out by the physician. Further, Grandhige et al. (18) reported that while 47.5% of the RTs in their study would have liked to be included in the family meeting to discuss MV withdrawal, only 6.6% of the RTs were involved in those meetings. Finally, Grandhige et al. (18) reported that 67.2% of the RTs in their

study felt that the ICU team communicated with them directly regarding the TE process when it was chosen for MV withdrawal.

Specific to nurses and physicians, Robert et al. (10) compared Job Strain Scores (JSS) in relation to TE and TW among ICU nurses, nursing assitants, senior physicians, and resident physicians. Their analysis found no significant differences between the groups across the total scores of the JSS. However, when examining the components of the JSS, they reported that TW carried a higher demand for nurses compared to TE. Robert et al. (10) also report that TE made for higher control and stronger social support for nursing assistants as well as senior and resident physicians than TW. TE was also associated with lower satisfaction with end-of-life care among resident physicians compared to TW. Accordingly, Robert et al. (10) found TE to be better for the psychological welfare of the ICU clinicians. However, it is important to note that Robert et al. (10) did not report on what each of the JSS domains reflected in terms of concrete descriptions or examples and consequently limited applicability of the findings.

The current literature makes evident the contextual and variable nature of the process of MV withdrawal within the context of end-of-life care in the ICU. The aim of this study was therefore to: 1) describe the processes of terminal weaning and terminal extubation; and, 2) compare where possible the similarities and differences in process and practices across two ICUs within one academic setting.

Methods

Design

The study design was a secondary data analysis using data previously collected as part of a longitudinal retrospective chart audit from a larger multi-method study. The use of the patient chart allowed for the collection of rich, detailed data from a patient's admission to the ICU until

the time of their death. The design was also retrospective in that all data collection was carried out after patients underwent WLSM and died. This design was selected because it enabled an examination of WLSM processes that were carried out over time and to establish sequences for those processes (19).

Setting

The study took place in two Level 3 medical-surgical ICUs at a large academic health sciences centre in Ontario, Canada. These ICUs are situated within a catchment area of approximately 1.3 million people. At the time of data collection there was a total of 56 beds (28 beds in each unit). Site A provides thoracic surgery and sees a higher volume of oncology related admissions (including bone and hematopoietic stem cell transplantation) compared to Site B which is the designated regional trauma center and houses both the vascular and neurosurgical programs. There were approximately 400 ICU nurses across both sites and a team of 21 intensivists (ICU physicians). RTs also provided direct patient care in both units and were available 24 hours per day. Given that RTs are not designated specifically to the ICU but rotate in and out of the unit, it was difficult to provide a total number of RTs in the ICU.

Sample

Data was collected between May and September of 2019. Patient charts from 2017 were purposefully chosen for this study. The reason being that in 2017, paper-based charting was available at both sites. In 2018, the organization began to transition towards an electronic health record. As a result, 2017 provided a snapshot whereby practices at both sites were static and not influenced by impending organizational changes. From the primary dataset, a total of 78 charts were included for this secondary data analysis. All charts involving patients receiving invasive mechanical ventilation at the time of initiation of WLSM were included.

Data Collection and Analysis

The primary data collection was completed using a 17-section data extraction form that was developed based on the patient medical chart with the nursing flow sheet being the primary source of data. Each section was designed to capture pertinent information regarding the dying and WLSM processes in the ICU from patient admission to the ICU ntil patient death. The form captured data such as those related to patient demographics, medical history, reasons for ICU admission, cause of death, family meeting, the decision to undertake WLSM, the processes of WLSM (i.e., mechanical ventilation and vasoactive medications), and the use of sedative, analgesic and adjunct agents. The tool was piloted across 21 randomly selected charts from both study sites. The piloting process was iterative and involved regular review by the primary and secondary authors. Data collection commenced once the tool produced satisfactory and consistent results. Data was collected between May and September of 2019. Piloted charts were not included in the final sample.

For the secondary analysis, data fields from the primary study were carefully selected and pertinent to the stated objectives. Once fields were selected, raw data that had been inputted into IBM Version 25 SPSS® were analyzed.

Descriptive statistical analysis was completed. Descriptive statistics were chosen as they allowed the student to answer the research objectives and to demonstrate the process of MV withdrawal during WLSM. Variables were clustered into tables that aim to address the research objectives and will be discussed as such in this thesis. Frequency tables were created for nominal level variables and descriptive statistics such as mean, standard deviation (SD), median, minimum, and maximum were calculated for ordinal, ratio, and interval level variables (Polit,

2010). Our rationale in choosing those statistics was twofold. First, most available literature on the topic of TE and TW have reported either the mean and SD, or the median and interquartile (IQR) range as evident in the systematic review done by Efstathiou et al. (8). To compare our findings to the literature, we chose to include all those measurements, except we chose to replace IQR with minimum and maximum as the latter statistic considers outliers within the data unlike IQR. We argue that the outliers are inseparable from the sample and provide for additional context description. Second, being a purely descriptive study, our purpose is to provide the readers with statistics that help them visualise how the data was distributed. The minimum and maximum represent the end points of our data, while the median represents the point at which the sample is split into two halves. The mean and SD serve to illustrate how the data was influenced by the outliers.

Ethical Considerations

The primary research study was approved by the Research Ethic Board (REB) of the University of Ottawa, as well as the REB of the participating acute care institution. All data used for this secondary analysis was already de-identified.

Results

A total of 78 patient charts were included in this study. Twenty-eight records were obtained from Site A, while 50 were from site B. The charts were divided into three groups. The first group, TW, (n= 43) included patients who underwent TW as a method of MV withdrawal. The second group, TE (n=26), included patients who had MV terminated (e.g., extubated or transitioned to t-piece) in one-step. While identified literature described transitioning to a t-piece as a part of TW rather than TE, we chose to group cases where patients were transitioned to a t-piece with the TE group instead. The rationale was that we viewed the termination of mechanical

ventilation as the distinctive criterion between the two groups. Patients who had MV terminated in one step were assigned to the TE group, whereas those who had MV terminated over multiple steps were assigned to the TW group. The removal of the endotracheal tube was examined both across and within those groups. The third group (n=9) included cases where MV was not withdrawn during the process of WLSM.

In our sample, the average patient age at admission to ICU was 68.3 years (SD=15.1). The average length of stay in ICU for the entire sample was 3.84 days (SD=3.71). Almost two-thirds of the patients (62.8%, n=49) were documented as being male. The majority of the sample (74.4%, n=58) were admitted to ICU with a level of care that included all invasive medical management including cardio-pulmonary resuscitation (CPR). About 15.4% (n=12) of patients were admitted to ICU with a level of care that accepted all intensive care except CPR. Interestingly, 10.2% (n=8) of the patients were admitted to the ICU regardless of having a level of care that excluded ICU admission from patient care. Table 1 further details the sample in terms of age, sex, length of ICU stay, and level of care.

Table 1 Sample Description

			Site A (n=28)				**Site B** (n=50)				**Total** (n=78)			
			TW (n=22)	**TE** (n=2)	**NW** (n=4)	**ST** (n=28)	**TW** (n=21)	**TE** (n=24)	**NW** (n=5)	**ST** (n=50)	**TW** (n=43)	**TE** (n=26)	**NW** (n=9)	**SaT** (n=78)
Age (years)	Mean		63.1	86.0	64.9	65.0	71.6	70.4	63.4	70.2	67.3	71.6	64.1	68.3
	SD		15.5	8.3	7.0	15.2	13.8	16.0	13.9	14.8	15.2	16.0	10.8	15.0
	Median		66.4	86.1	62.7	66.4	72.5	73.9	69.3	72.4	71.3	76.0	63.2	72.2
	Min-Max		30.7-88.8	80.2-92.0	59.0-75.1	30.7-92.0	32.8-92.8	26.3-88.2	45.7-78.5	26.3-92.8	30.7-92.8	26.3-92.0	45.7-78.5	26.3-92.8
ICU length of stay (days)	Mean		4.87	2.30	2.61	4.37	4.41	3.31	1.13	3.55	4.65	3.23	1.79	3.84
	SD		3.82	2.92	4.69	3.89	4.20	3.22	.87	3.62	3.97	3.16	3.04	3.71
	Median		5.02	2.30	.31	4.11	3.03	2.19	1.19	2.19	3.85	2.19	.44	2.35
	Min-Max		.40-16.3	.24-4.36	.18-9.65	.18-16.3	.16-15.9	.15-12.6	.23-2.42	.15-15.9	.16-16.3	.15-12.6	.18-9.65	.15-16.3
Sex	Male	N	15	2	3	20	14	12	3	29	29	14	6	49
		%	68.2	100	75	71.4	66.7	50	60	58	67.4	53.8	66.7	62.8
	Female	N	7	0	1	8	7	12	2	21	14	12	3	29
		%	31.2	0	25	28.6	33.3	50	40	42	32.6	46.2	33.3	37.2
Level of Care	Cat 1	N	17	0	4	21	18	15	4	37	35	15	8	58
		%	77.3	0	100	75	85.7	62.5	80	74	81.4	57.7	88.9	74.4
	Cat 2	N	4	1	0	5	2	4	1	7	6	5	1	12
		%	18.2	50	0	17.9	9.5	16.7	20	14	14	19.2	11.1	15.4
	Cat 3	N	1	1	0	2	1	5	0	6	2	6	0	8
		%	4.5	50	0	7.1	4.8	20.8	0	12	4.6	23.1	0	10.2

TW: Terminal weaning group TE: Terminal extubation group NW: No withdrawal group ST: Site total SaT: Sample total Cat 1: Full Invasive Care Cat 2: Full Invasive Care but no CPR Cat 3: No Invasive Care or admission to ICU

The most common reasons for ICU admission were neurological (39.7%, n=31), respiratory (23.1%, n=18), and cardiovascular (20.5%, n=16). The most common pre-existing medical conditions across the sample were hypertension (50%, n=39), dyslipidemia (31.6%, n=25), and diabetes mellitus type two (24.4%, n=19). The most frequently recorded causes of death for the sample were neurological (47.4%, n=37), and respiratory (23.1%, n=18). A family meeting to discuss WLSM was held in 98.7% (n=77) of the cases. The average duration from patient admission to the family meeting was 3.16 days (SD=3.54). Patient families were present at the time of death in 94.8% (n=74) of all cases.

Specific to MV withdrawal processes, the most common ventilation mode across the entire sample at the initiation of WLSM was pressure support ventilation (PSV) (42.3%, n = 33). The average length of MV for the sample was 74.3 hours (SD = 78.3). The average FiO_2 used in the sample was 46% (SD = 24) and the mean positive end expiratory pressure (PEEP) was 9 cm of H_2O (SD = 3). Nearly half of the patients (47.4%, n = 37) were not on any vasoactive infusions at the start of WLSM. Table 2 further describes the samples in regard to the use of life-sustaining measures prior to WLSM.

Table 2 Life-Sustaining Measures Use Prior to Withdrawal

			Site A (n=28)				**Site B** (n=50)				**Total** (n=78)			
			TW (n=22)	**TE** (n=2)	**NW** (n=4)	**ST** (n=28)	**TW** (n=21)	**TE** (n=24)	**NW** (n=5)	**ST** (n=50)	**TW** (n=43)	**TE** (n=26)	**NW** (n=9)	**SaT** (n=78)
Ventilation mode prior to WLSM	SIMV	N	1	0	1	2	11	12	3	26	12	12	4	28
		%	4.5	0	25	7.1	52.4	50	60	52	27.9	46.2	44.4	35.9
	CPAP /PSV	N	9	1	1	11	9	11	2	22	18	12	3	33
		%	41	50	25	39.3	42.9	45.8	40	44	41.9	46.2	33.3	42.3
	ACV	N	11	1	2	14	1	1	0	2	12	2	2	16
		%	50	50	50	50	4.7	4.2	0	4	27.9	7.6	22.2	20.5
	PCV	N	1	0	0	1	0	0	0	0	1	0	0	1
		%	4.5	0	0	3.6	0	0	0	0	2.3	0	0	1.3
FiO_2 prior to WLSM	Mean		54	25	80	56	37	39	63	41	46	38	71	46
	SD		27	0	40	30	9	19	35	19	22	19	36	24
	Median		43	25	100	43	35	33	50	35	40	30	100	35
	Min-Max		25-100	25-25	21-100	21-100	25-55	30-100	24-100	24-100	25-100	25-100	21-100	21-100
PEEP prior to WLSM (cm H_2O)	Mean		10	10	10	10	8	8	7	8	9	8	8	9
	SD		3	0	0	2	3	2	2	3	3	2	2	3
	Median		10	10	10	10	8	8	5	8	8	8	10	8
	Min-Max		6-18	10-10	10-10	6-18	5-14	5-16	5-10	5-16	5-18	5-16	5-10	5-18
Length of mechanical ventilation (hours)	Mean		92.7	16.7	5.62	74.8	93.3	66.8	28.2	73.9	93.0	62.6	18.1	74.3
	SD		88.2	9.37	1.67	85.3	86.3	68.7	19.9	75.0	86.2	66.4	18.4	78.3
	Median		71.1	16.7	5.70	36.9	74.1	51.6	29.0	48.6	74.1	48.6	8.68	46.8
	Min-Max		9.67-386	10.1-23.3	3.83-7.25	3.83-386	6.0-287	3.08-281	8.86-58.3	3.08-287	6.0-386	3.08-274	3.83-58.3	3.08-386
Vasopressors prior to WLSM	0	N	4	2	1	7	13	14	3	30	17	16	4	37
		%	18.2	100	25	25	62	58.3	60	60	39.5	61.5	44.4	47.4
	1-2	N	12	0	1	13	4	6	1	11	16	6	2	24
		%	54.5	0	25	46.4	19	25	20	22	37.2	23.1	22.2	30.8
	3-5	N	6	0	2	8	4	4	1	9	10	4	3	17
		%	27.3	0	50	28.6	19	16.7	20	18	23.2	15.4	33.3	21.8

TW: Terminal weaning group TE: Terminal extubation group NW: No withdrawal group ST: Site total SaT: Sample total

Mechanical Ventilation Withdrawal

At Site A, 78.6% (n=24) of patients underwent TW, 7.1% (n=2) underwent TE, and 14.3% (n=4) had no MV withdrawal done. In comparison, at Site B 42% (n=21) of patients underwent TW, 48% (n=24) patients underwent TE, and 10% (n=5) had no withdrawal. Patients who did not have MV withdrawn had shorter ICU stays, shorter durations of mechanical ventilation, and higher FiO_2 needs.

In the TW group across both sites, the period from the start of MV to the first step of WLSM was 91.7 hours on average (SD = 85.9). The average period from first change in MV to the patient's death was 9.19 hours (SD = 13.6). The average period from last change in MV to the patient's death was 7.82 hours (SD = 12.9). A T-piece was used in 18.6% (n = 8) of the patients and about 53.5% (n = 23) of the patients were extubated at the end of the TW process. Signs of respiratory distress were documented in 60.5% (n = 26) of the TW group and 43.5% (n = 10) of patients extubated during the TW process had documented signs of upper airway obstruction.

In the TE group for contrast, the period from the start of MV to termination of MV was 62.7 hours on average (SD = 66.4). The period from the termination MV to the patient's death was on average 15.8 hours (SD = 22.8. A T-piece was used in 7.7% (n = 2) of the patients and about 92.3% (n = 24) of the patients were extubated. Further, 65.4% (n = 17) of patients in the TE group had documented signs of respiratory distress and 41.7% (n = 10) of patients extubated with the TE process had documented signs of upper airway obstruction. Table 3 further details the comparison between the TW and TE groups.

Table 3 Mechanical Ventilation Withdrawal

			Site A (n=24)			**Site B** (n=45)			**Total** (n=69)		
			TW (n=22)	**TE** (n=2)	**ST** (n=24)	**TW** (n=21)	**TE** (n=24)	**ST** (n=45)	**TW** (n=43)	**TE** (n=26)	**SaT** (n=69)
Period from the start of MV till the first step of withdrawal (hours)	Mean		91.2	16.7	84.9	92.1	66.8	78.4	91.6	62.9	80.7
	SD		88.1	9.37	86.8	85.8	68.7	76.9	85.9	67.3	79.9
	Median		71.1	16.7	52.6	73.2	51.6	53.0	73.2	48.6	53.0
	Min-Max		8.92-386	10.0-23.3	8.92-386	5.08-286	3.08-282	3.08-286	5.08-386	3.08-282	3.08-386
Period from the first change in MV during WLSM to patient death (hours)	Mean		7.18	3.98	6.91	11.3	16.8	14.2	9.19	15.8	11.7
	SD		11.6	4.67	11.1	14.8	23.4	19.9	13.3	22.8	17.6
	Median		1.45	3.98	1.45	4.92	3.98	4.75	2.67	3.98	3.32
	Min-Max		.08-41.5	.67-7.30	.08-41.5	.33-59.5	.05-80.2	.05-80.2	.08-59.5	.05-80.2	.05-80.2
Period from the last change in MV during WLSM to patient death (hours)	Mean		5.63	3.98	5.50	10.1	16.8	13.6	7.82	15.8	10.8
	SD		10.5	4.69	10.1	14.9	23.4	20	12.9	22.8	17.6
	Median		.65	3.98	.67	3.67	3.98	3.67	.88	3.98	1.25
	Min-Max		.08-38.7	.67-7.30	.08-38.7	.08-58.3	.05-80.2	.05-80.2	.08-58.3	.05-80.2	.05-80.2
Use of T-piece		N	6	1	7	2	1	3	8	2	10
		%	27.3	50	29.2	9.5	4.2	6.7	18.6	7.7	14.5
Extubation		N	5	1	6	18	23	41	23	24	47
		%	22.7	50	25	85.7	95.8	91.1	53.5	92.3	68.1
Documented signs of respiratory distress		N	12	1	13	14	16	30	26	17	43
		%	54.5	50	54.2	66.7	66.7	66.7	60.5	65.4	62.3
Documented signs of upper airway obstruction after extubation		N	1	0	1	9	10	19	10	10	20
		%	20	0	16.7	50	43.5	46.3	43.5	41.7	42.6

TW: Terminal weaning group TE: Terminal extubation group ST: Site total SaT: Sample total

From the TW group, two other subgroups were created. One included patients who had MV terminated (t-piece) using TW but not extubated (9.3%, n = 4), while the other included those who were extubated at the end of TW (53.5%, n = 23). The average length of the weaning process was 1.37 hours (SD = 1.93) for patients in the TW group, 2.32 hours (SD = 3.26) for patients who had MV terminated but were not extubated, and 1.03 hours (SD = 0.83) for those who were extubated at the end of TW. On average, the weaning process involved one ventilation mode change (SD = 1) and three ventilation parameters changes (SD = 2). Table 4 further details the process of weaning within the sample and across the two sites.

Table 4 Terminal Weaning

			TW			T-piece with TW			Extubated with TW		
			Site A (n=22)	**Site B** (n=21)	**Total** (n=43)	**Site A** (n=4)	**Site B** (n=0)	**Total** (n=4)	**Site A** (n=5)	**Site B** (n=18)	**Total** (n=23)
Duration of the weaning process (hours)	Mean		2.00	1.26	1.60	2.32	-	2.32	1.48	.91	1.03
	SD		2.26	1.73	1.99	3.26	-	3.26	.99	.77	.83
	Median		1.00	.88	.92	.93	-	.93	.83	.88	.83
	Min-Max		.23-7.77	.08-7.92	.08-7.92	.23-7.17	-	.23-7.17	.73-2.8	.08-2.58	.08-2.80
Ventilation mode changes (e.g. from PCV to CPAP) during the weaning process	Mean		1	1	1	1	-	1	2	2	2
	SD		1	1	1	1	-	1	1	1	1
	Median		1	1	1	1	-	1	2	1	1
	Min-Max		0-2	0-3	0-3	1-2	-	1-2	1-2	1-3	1-3
	0	N	7	3	10	0	-	0	0	0	0
		%	31.8	14.3	23.3	0	-	0	0	0	0
	1	N	11	11	22	3	-	3	2	11	13
		%	50	52.4	51.2	75	-	75	40	61.1	56.5
	2	N	4	5	9	1	-	1	3	5	8
		%	18.2	23.8	20.9	25	-	25	60	27.8	34.8
	3	N	0	2	2	0	-	0	0	2	2
		%	0	9.5	4.6	0	-	0	0	11.1	8.7
Ventilation parameters (PEEP, PS, RR, FiO_2) changes during the weaning process	Mean		4	3	3	4	-	4	3	3	3
	SD		2	1	2	2	-	2	1	1	1
	Median		4	3	3	3	-	3	3	3	3
	Min-Max		1-10	0-6	0-10	2-7	-	2-7	1-5	0-6	0-6
	0	N	0	1	1	0	-	0	0	1	1
		%	0	4.8	2.3	0	-	0	0	5.6	4.3
	1-2	N	6	6	12	1	-	1	1	6	7
		%	27.3	28.6	27.9	25	-	25	20	33.2	30.4
	3-5	N	14	13	27	2	-	2	4	10	14
		%	63.6	61.8	62.8	50	-	50	80	55.6	60.9
	6-10	N	2	1	3	1	-	1	0	1	1
		%	9.1	4.8	7	25	-	25	0	5.6	4.3

TW: Terminal weaning MV: Mechanical ventilation

Discussion

This study contributes to the body of literature that illustrates the complexity and the nuances of MV withdrawal within the context of end-of-life care in the ICU. It details the contextual variability in the practices of MV withdrawal. Within our sample of 78 patients, 88.5% (n = 69) of the patients who were receiving MV at the start of WLSM had it withdrawn using either TW or TE. This is consistent with the findings brought forward by Epker et al. (9) and further supports that the withdrawal of MV is a common practice during end-of-life care in the ICU. TW was utilized in 62.3% (n = 43) of the cases while TE was used in 37.7% (n = 26). These rates reflect a higher practice of TE as a MV withdrawal method at the study sites as compared to those studies conducted in France by Cottereau et al. (17) and Thellier et al.. (5) In the current study, 92.3% (n = 24) of MV withdrawal using TE was done at Site B. This might be attributed to the fact that Site B primarily serves neurological and trauma patients, who mostly require MV for airway protection rather than respiratory support for acute respiratory failure (1). However, as highlighted in Table 3, patients at Site B who underwent TE had similar or higher FiO_2 and PEEP requirements compared to those who underwent TW. At Site A for comparison, the patients who underwent TE had significantly lower FiO_2 needs and similar PEEP requirements. Interestingly, however, patients who underwent TE at both sites had shorter average length of MV than those who underwent TW. Those two findings may suggest that the choice of MV withdrawal method is likely influenced by length of time on MV, as well as the centers' and clinicians' practices rather than the patient's pathophysiology and ventilatory support requirements.

In this study, patients' families were present at the time of death in all cases of TE and 93% (n = 40) of the TW cases. This supports the finding reported by Thellier et al. (5) suggesting

higher chances of family presence at time of death with TE versus TW. However, regardless of the method of MV withdrawal, patient families are more likely to be present than not at the time of patient death. Accordingly, ICU clinicians, and particularly ICU nurses, should strive to prepare the patient's families for what the withdrawal process might look like and the possible signs and symptoms the patient might show. Further, the patient's families ought to be provided with appropriate emotional and spiritual support (20). In studies that have explored ICU nurses' experiences of caring for patients during the WLSM, it is evident that family presence is a priority (21).

The average duration from the last change to MV (mode or parameter) to patient death in the sample was 10.84 hours (SD = 17.55). Patients died anywhere between three minutes to 80 hours and 13 minutes, with a median of 75 minutes. This median is longer than the average median of 61.7 minutes reported by Efstathiou et al. (8). Further, patients who underwent TW in the current study died sooner than those who underwent TE. This finding contradicts findings reported by Thellier et al. (5) and Robert et al. (10) suggesting that patients died sooner after TE compared to TW. This highlights that the method of MV withdrawal is one among numerous factors that determine the duration from MV withdrawal to patient death. Other factors may include the patient physiological condition, the use of other life-sustaining measures, and length of time on MV (8).

Findings from this study indicate that many patients experience some respiratory distress during the process of MV withdrawal. When comparing TW to TE, 60.4% (n = 26) of the patients in the TW group had documented signs of respiratory distress during or after TW, while 65.4% (n = 17) of patients within the TE group had similar signs documented after TE. These rates surpass the 50% reported by Robert et al. (13) and emphasizes that the withdrawal of

MV carries the risk of patient discomfort. Our findings suggest that there is little difference between the two methods in terms of associated patient respiratory distress. Further, the prevalence of upper airway obstruction after extubation among patients who underwent TW was 43.5% (n = 10) versus 41.6% (n = 10) for those extubated via TE. This affirms that both methods carry a similar risk of upper airway obstruction after patient extubation. These findings challenge those provided by Robert et al (10) suggesting higher incidences of airway obstruction associated with TE over TW. Accordingly, regardless of the method of MV withdrawal, ICU nurse is ought to work to anticipate and proactively manage any patient distress during and after the withdrawal of MV (20).

This study is the first of its kind to describe the process of terminal weaning rather than to evaluate a specific weaning protocol. Weaning took anywhere between 5 minutes to 7 hours and 46 minutes, and involved anywhere between zero to three ventilation modes changes, and zero to ten ventilation parameters changes. The extended time span and the multiple steps involved in TW provide a theoretical support to TW being more attuned to patient comfort than TE. However, the prevalence of respiratory distress and upper airway obstruction were similar between the TE and TW group. Accordingly, ICU clinicians should not consider one method to be superior to the other. Instead, the choice of method should be based on thorough consideration of the patient's situation and tailored to optimize comfort and minimize distress for both the patient and their family. This is consistent with the recommendation provided by Downar et al. (7) for process of MV withdrawal to be individualized for each patient with comfort as a focus and that invasive ventilation be withdrawn "as quickly as comfort allows" (p. 1012).

Limitations

The sample was relatively small, and Site B composed 64% of the sample (n = 50), while Site A only provided 36% of charts (n = 28). This could have contributed to the practices of Site B being more predominant in our sample and overshadowed the practices of Site A. Accordingly, findings are presented across sites as well as across groups to help reflect the practices of each site and ensure fair representation.

The second limitation is related to the source of the data in our study. Being a chart audit study, the quality of data is determined by the quality of the documentation in the patients' medical records. Accordingly, some variables may have been misrepresented due to inaccurate or incomplete documentation. Further, the researchers were unable to objectively quantify some variables such as the presence of respiratory distress or upper airway obstruction, instead, we were only able to report whether those variables were documented in the patients' chart or not. Consequently, some incidents of respiratory distress and upper airway obstruction might not have been accurately assessed. Further with no consistent measure of distress or obstruction, documentation was reflective of the subjective interpretation of the care provider at the bedside – namely, the ICU nurse.

Implications and Conclusion

This study further highlights the nuanced and complex nature of MV withdrawal during end of life in the ICU. While the choice of MV withdrawal method remains variable, the care associated with it remains constant and paramount. The goal of end-of-life care remains to ensure patients and family comfort, minimize distress, and facilitate a "good death". Accordingly, all ICU clinicians, particularly those who carry out the processes of WLSM such as ICU nurses or respiratory therapists, should be familiar with the various methods of WLSM,

their application and how those methods impact the patients and their families. While clinicians' practices and preferences play a role in choosing among the methods of WLSM, they should not be the only factor - patients' and families' preferences and level of comfort should also be considered during the WLSM. Further research is needed to compare the methods of WLSM, particularly, the methods of MV withdrawal and examine the advantages of one approach over the other.

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Chapter 5: Integrated Discussion

In this chapter, I discuss the findings of this study as they relate to the current literature. This chapter is divided into three sections. Section 1 is a discussion of the findings related to the processes and practices of MV withdrawal and is specific to thesis Objective 1 and 2. Section 2 present findings that were outside of the scope of the manuscript (Chapter 4) and focuses on thesis Objective 3. A discussion of the utilization of the Comfort Care Orders (CCO) and congruence with what was found in the data is provided. Lastly, Section 3 provides a focused discussion of the ICU nurse's role in end-of-life care and WLSM. Implications for nursing practice, education, and research are provided followed by limitations and a concluding statement.

Section 1: Discussion of Mechanical Ventilation Withdrawal Processes and Practices

In this section, I discuss MV withdrawal processes and practices as they relate to thesis Objectives 1 and 2: *To describe in detail the processes of terminal weaning and terminal extubation; and, to compare, where possible, the similarities and differences in processes and practices across sites.* To meet those, a secondary data analysis was conducted using descriptive statistical analyses of 78 qualifying patient's medical charts from the primary retrospective longitudinal study. The sample was divided into groups based on study site and MV withdrawal methods. Variables were examined for each of the groups to determine similarities and differences across the groups.

Summary of Findings

In the study reported in this thesis, MV was withdrawn in 88.5% (n=69) of the 78 patients undergoing WLSM within the context of end-of-life care in the ICUs of the study setting. When withdrawing MV, TW was used in 62.3% (n=43) of the cases while TE was used

for the remainder 37.7% (n=26) of the patients. In comparing TW versus TE, patients who underwent TW were on average younger [67.3 years (SD=15.2) vs 71.6 years (SD= 16)], had a longer ICU stay [4.7 days (SD=4) vs 3.2 days (SD=3.2)], had higher FiO_2 requirements [46% (SD=22) vs 38% (SD=19)] and PEEP requirements [9 cm H_2O (SD=3) vs 8 cm H_2O (SD=2)], had a longer duration of invasive MV [93 hours (SD=86.2) vs 62.7 hours (SD=66.4)], shorter period from first change MV to patient death [9.2 hours (SD=13.3) vs 15.8 hours (SD=22.8)], shorter period from last change MV to patient death [7.8 hours (SD= 12.9) vs 15.8 hours (SD=22.8)], had slightly lower rates of respiratory discomfort [60.4% (n=26) vs 65.4% (n=17)], and had similar rates of airway obstruction after extubation [43.5% (n=10) vs 41.7% (n=10)]. In patients who underwent TW, the weaning process lasted an average of an hour and thirty-two minutes (SD= 2.15) and entailed a mean of one ventilation mode change (SD=1) and three ventilation parameter changes (SD= 2). The TW process resulted in termination of MV in 62.8% (n=27) of the cases, with the patient being placed on a T-piece in 9.3% (n=4) of the cases, and in patient extubation in 53.5% (n=23) of the patients.

Frequency of mechanical ventilation withdrawal

Within our sample, 88.5% (n=69) of the patients who were receiving MV at the start of WLSM had it withdrawn using either TW or TE. This is consistent with the finding brought forward by Epker et al. (2015) in the Netherlands and further supports that the withdrawal of MV is a common practice during end-of-life care in the ICU. Analysis from this current study showed that the 11.5% (n=9) of cases for whom MV was not withdrawn as a part of the WLSM process were on average; younger [64.0 years (SD= 10.8)], had an ICU stay of less than two days [1.79 day (SD= 3)], had higher FiO_2 needs [71% (SD=36)], and shorter average duration of mechanical ventilation [18.2 hours (SD=18.4)].

Comparing TW and TE.

Utilization Rates.

Within our sample, TW was utilized in 62.3% (n=43) of the cases, while TE was used in remaining 38% (n=26). These rates reflected a higher usage of TE as a MV withdrawal method in our organization than those provided by Cottereau et al. (2016) or Thellier et al. (2017) in France. In our sample, 92.3% (n=24) of MV withdrawal using TE was done in Site B. This might be attributed to the fact that site B primarily serves neurological and trauma patients, who mostly require MV for airway protection as opposed to respiratory support (Potchileev et al., 2021), and therefore weaning can be viewed as not entirely necessary. However, as highlighted in Table 2 in Chapter 4 (see p. 59), patients at Site B who underwent TE had similar or higher FiO_2 and PEEP requirements compared to those who underwent TW. At Site A for comparison, patients who underwent TE had significantly lower FiO_2 needs and similar PEEP requirements, however, this finding should be interpreted with caution given the limited sample size. Interestingly, however, patients who underwent TE at both sites had shorter average length of MV than those who underwent TW. This may suggest that the choice of MV withdrawal method is likely influenced by length of MV, as well as centre and clinician practices/preferences rather than the patient's pathophysiology and ventilatory support requirements. A possible explanation for the difference in utilization rate between the two ICUs is that the pre-printed Comfort Care Orders (CCO), which use TW as the MV withdrawal method, was initially developed and used at Site A, and then moved and applied in Site B. Accordingly, clinicians in Site A had more familiarity working with and following the CCO, which is reflected in the higher utilization rates (100% (n=28) for Site A vs 70% (n=35) for Site B). A more comprehensive discussion of the CCO is provided in Section 2.

Patient Impact.

The average duration from the last change to MV (mode or parameter) to patient death in our sample was 10.84 hours (SD= 17.55). Patients died anywhere between three minutes to 80 hours and 13 minutes, with a median of 75 minutes. This median is longer than the average median of 61.7 minutes reported by the systematic review of multiple studies done by Efstathiou et al. (2020). Further, patients who underwent TW in our sample died more quickly than those who underwent TE [7.8 hours (SD=12.9) vs 15.8 hours (SD=22.8)]. This finding contradicts that provided by Thellier et al. (2017) suggesting that patients died sooner after TE compared to TW. This highlights that the method of MV withdrawal is one among numerous factors that may influence the duration from MV withdrawal to patient death. Other factors may include the patient physiological condition, the use of other LSMs, and length of MV (Efstathiou et al., 2020). According to Munshi et al. (2015), those factors, along with patient Glasgow Coma Scale score, and brain stem reflexes have been identified as consistent predictors for time of death after WLSM irrespective of the mode of MV withdrawal.

Findings from our study indicate that many patients experience some respiratory distress during the process of MV withdrawal. When examining respiratory distress symptoms in our sample, we found that 62.3% (n=43) of the patients who underwent MV withdrawal had documented signs of respiratory distress. This rate surpasses the 50% reported by Robert et al. (2020) and emphasizes that the withdrawal of MV carries significant chances of patient discomfort. Further, when comparing TW to TE, 60.4% (n=26) of the patients in the TW group had documented signs of respiratory distress during or after TW, while 65.4% (n=17) of patients within the TE group had similar signs documented after TE. These results suggest that there is

little difference between the two methods in terms of associated patient respiratory distress. The prevalence of upper airway obstruction after extubation among patient who underwent TW was 43.5% (n=10) versus 41.6% (n=10) for those extubated via TE. This affirms that both methods carry a similar risk of upper airway obstruction after patient extubation. These findings challenge those provided by Robert et al. (2017) suggesting higher incidences of airway obstruction associated with TE over TW. However, it is important to note that the identification of respiratory distress and upper airway obstruction in our study was based on the ICU nurse's subjective assessment and documentation. This may have contributed to some incidents being missed or inaccurately represented. Further, this type of identification does not allow for comparative analysis in terms of severity, duration, or other qualities of respiratory distress and upper airway obstruction. Future studies should employ validated assessment tools such as the respiratory distress observation scale (RDOS) (Campbell, 2008) to allow comparison and quantification of respiratory distress and upper airway obstruction during and after the withdrawal of MV. The case remains that regardless of the method of MV withdrawal, anticipatory and proactive management of patient distress is a foundational component of MV withdrawal and end-of-life care in the ICU.

Family Presence.

In our sample, a family meeting was held to discuss WLSM in all but one case (98.7%, n=77). In this one ptient, the ICU team was unable to identify any of the patient's family and the decision-making role was deferred to the office of Public Guardian and Trustee. Further, patients' families were present at the time of death in all cases of TE (n=26) and 93% (n=40) of the TW cases. This supports the finding reported by Thellier et al. (2017) suggesting higher chances of family presence at time of death with TE versus TW. However, regardless of the

method of MV withdrawal, patients' families are more likely to be present than not during the WLSM process and at the time of patient death (Gerstel et al., 2008; Robert et al., 2017; Wiegand, 2016; Wiegand et al., 2019). Family members' experiences of WLSM and patient death can leave them with significant psychological challenges such as Post-Traumatic Stress Disorder (PTSD), anxiety and depression, and complicated grief (Kentish-Barnes et al., 2015; Robert et al., 2017). While all ICU clinicians play a role in caring for and supporting the patients' families, the ICU nurses takes on a pivotal role in caring for families as they witness the death of their loved ones (Long-Sutehall et al., 2011; Noome et al., 2016). The role of the ICU nurse in the process of WLSM and in end-of-life care will be discussed in section 3 of this chapter.

Terminal Weaning

Our study appears to be the first of its kind to describe the process of terminal weaning rather than to evaluate a specific weaning protocol. Weaning took anywhere between five minutes to seven hours and 46 minutes, and involved anywhere between zero to three ventilation modes changes, and zero to ten ventilation parameters changes. Further, TW resulted in the termination of MV in 62.8% (n=27) of patients and extubation in 53.5% (n=23) of the patients. Patients were extubated using TW over an average of one hour (SD =0.8). The extended time span and the multiple steps involved in TW provide support to TW being more attuned to patient comfort than TE. However, ICU clinicians ought not consider one method to be superior to the other. Instead, they should understand that patients die differently in the ICU and thus the choice of MV withdrawal method should be based on thorough consideration of patients' status and tailored to optimize comfort and minimize distress for both patients and their families.

Outliers and Standardization of the Withdrawal of Life Sustaining Measures

Within our sample, outliers were common across the ratio and interval level variables. In terms of patient age, our analysis identified four outliers that were patients less than 33 years old (32.8, 20.72, 27.3, and 26.3 years). There were two outlier cases where the patients had ICU lengths of stay longer than 15 days (16.3 and 15.9 days). The same two patients had outlier values for the period from admission to the ICU to the WLSM family meeting that were also longer than 15 days (15.6 and 15.6 days). Our analysis identified eleven outliers of 100% FiO_2 within our sample, and another one of 18 cm H_2O of PEEP. In terms of the length of MV, three outliers (287.7, 282.6, and 281.9 hours) and one extreme outlier (386.9 hours) were identified in our sample. The same cases had outlier values for the period from MV start to the first change during WLSM (mild: 281.6, 281.9, and 285.7; extreme: 386.1 hours). The period from first change of MV during WLSM to patient death included four outliers (41.5, 41.7, 46.3, and 59.5 hours) and two extreme ones (71.8 and 80.2 hours). The period from the last change to MV during WLSM to patient death also contain two outliers (41.7 and 46.3 hours) and three extreme outliers (58.3, 71.80, and 80.2 hours). As for the duration of the weaning process, our analysis identified one outlier (7.17 hours) and two extreme outliers (7.9, 7.77). Finally, our analysis also identified twelve outliers in the count of ventilation mode changes during TW (3, 3, and 10 x 0 changes), and one outlier in the count of ventilation parameter changes during TW (10 changes).

The presence and the values of the identified outliers within our analysis, as well as the lack of clear advantage to one MV withdrawal method over the other, both signify the wide range of variability within death and dying in the ICU. This affirms that while some patients might die in a similar fashion, others die very differently. Accordingly, different patients die in the ICU for different reasons, and in different ways. Each case of WLSM, and each dying patient

ought to be viewed as unique. Choice of method of withdrawal should be tailored to address the patient's specific case rather than fit a standardized approach or a policy. Efforts to standardize the WLSM processes such as the WLSM checklist and order set by the Canadian Blood Services (2019) or the guidelines provided by Downar et al. (2016) ought to be approached with caution. While those efforts provide important clinical and educational resources toward a uniformed evidence-based practice, they also carry risks for simplification of a complex process and may result in inappropriate or inadequate care (Bruce, 2017; Church & Naugler, 2019). This necessitates that all ICU clinicians view standardized approaches to WLSM and end-of-life care in the ICU as *suggestions* and *recommendations* rather than clear cut practice guidelines. In fact, Downar et al (2016) in their discussion section acknowledged the "need to study the effect of implementing […] guidelines, in order to determine whether they actually result in improvements in patient care" (p.1014). Accordingly, it is imperative that all ICU clinicians are well educated regarding the core principles of end-of-life care and WLSM in the ICU, and that they are capable of assessing the patients' and the families' needs and tailoring care accordingly.

Section 2: Discussion of the Utilization of Comfort Care Orders

As previously described in Chapter 3, the Comfort Care Orders (CCO) is an order set that details how to initiate and provide comfort care as well as how to withdraw life-sustaining measures including mechanical ventilation. This discussion of the CCO is focused on the withdrawal of MV and the use of analgesia, sedation and symptoms management. Below is a brief overview of the findings related to thesis Objective 3.

Summary of Findings

In our sample, 80.8% (n=63) of patients had the CCO completed. Out of the 63 patients who had the CCO completed, 12.7% (n=8) had modifications to one or more of the components of CCO. Examples of modifications included maintaining vasopressor support and/or respiratory support at pre-WLSM levels, using fentanyl and propofol instead of hydromorphone and midazolam, and the addition of ketamine. Regarding MV withdrawal as described in the CCO, we found that 43.6% (n=34) of the patients within the sample had the mode of MV weaned to CPAP, 46.2% (n=36) had the FiO_2 weaned to 21%, 51.3% (n=40) had the PEEP weaned to 10 cm H_2O or less, 44.9% (n=35) had PS weaned to 10 cm H_2O or less, and only 21.8% (n=17) had a trial of PEEP of 5 cm H_2O and PS of 5 cm H_2O. For analgesia, while morphine was the drug suggested by the CCO, it was only used in 1.3% (n=1) of the cases as an infusion, and in 3.8% (n=3) of the cases as a bolus medication. Instead, morphine was often substituted with hydromorphone which was administered as an infusion in 85.9% (n=67) of cases, and as a bolus in 62.8% (n=49) of the cases. For sedation, midazolam was used as an infusion in 67.9% (n=53) of the cases and as a bolus in 62.8% (n=49) of cases. Finally, the only adjunct agent used in our sample was scopolamine at a rate of 21.8% (n=17) of the cases while sublingual atropine and

glycopyrrolate were not used in any of the cases. Table 5.1 presents a detailed representation of our findings.

Table 5.1. The Use of the Comfort Care Orders

		Site A (n=28)				**Site B** (n=50)				**Total** (n=78)			
		TW (n=22)	**TE** (n=2)	**NW** (n=4)	**ST** (n=28)	**TW** (n=21)	**TE** (n=24)	**NW** (n=5)	**ST** (n=50)	**TW** (n=43)	**TE** (n=26)	**NW** (n=9)	**SaT** (n=78)
Standard comfort orders signed	N	22	2	4	28	19	15	1	35	41	17	5	63
	%	100	100	100	100	90.5	62.5	20	70	95.3	65.4	55.6	80.8
Modification to standard comfort orders	N	4	0	1	5	2	1	0	3	6	1	1	8
	%	18.2	0	25	17.9	9.5	4.2	0	6	14	3.8	11.1	10.3
Ventilation mode weaned to CPAP during withdrawal	N	18	0	0	18	15	1	0	16	33	1	0	34
	%	81.8	0	0	64.3	71.4	4.2	0	32	76.7	3.8	0	43.6
FiO_2 weaned to 21% during withdrawal	N	20	0	0	20	16	0	0	16	36	0	0	36
	%	90.9	0	0	71.4	76.2	0	0	32	83.7	0	0	46.2
PEEP weaned to 10 or less cm H2O during withdrawal	N	19	0	0	19	21	0	0	21	40	0	0	40
	%	86.4	0	0	67.9	100	0	0	42	93	0	0	51.3
PS weaned to 10 or less cm H_2O during withdrawal	N	18	0	0	18	17	0	0	17	35	0	0	35
	%	81.8	0	0	64.3	81	0	0	34	81.4	0	0	44.9
PEEP=5 and PS=5 trail attempted during withdrawal	N	11	0	0	11	6	0	0	6	17	0	0	17
	%	50	0	0	39.3	28.6	0	0	12	39.5	0	0	21.8
Morphine infusion used	N	0	0	0	0	0	1	0	1	0	1	0	1
	%	0	0	0	0	0	4.2	0	2	0	3.8	0	1.3
Morphine used as a PRN agent	N	0	0	0	0	1	2	0	3	1	2	0	3
	%	0	0	0	0	4.8	8.3	0	6	2.3	7.7	0	3.8
Hydromorphone infusion used	N	22	2	4	28	18	18	3	39	40	20	7	67
	%	100	100	100	100	85.7	75	60	78	93	76.9	77.8	85.9
Hydromorphone used as a PRN agent	N	17	0	2	19	14	14	2	30	31	14	4	49
	%	77.3	0	50	67.9	66.7	58.3	40	60	72.1	53.8	44.4	62.8
Midazolam infusion used	N	20	2	3	25	12	15	1	28	32	17	4	53
	%	90.9	100	75	89.3	57.1	62.5	20	56	74.4	65.4	44.4	67.9
Midazolam used as a PRN agent	N	16	1	1	18	14	16	1	31	30	17	2	49
	%	72.7	50	25	64.3	66.7	66.7	20	62	69.8	65.4	22.2	62.8
Scopolamine used	N	2	0	0	2	7	8	0	15	9	8	0	17
	%	9.1	0	0	7.1	33.3	33.3	0	30	20.9	30.8	0	21.8

TW: Terminal weaning group TE: Terminal extubation group NW: No withdrawal group ST: Site total SaT: Sample total

Comfort Care Order Set Use across Study Sites

When comparing the utilization of the CCO across the two study sites, Site A had the CCO completed and signed for all 28 cases, while only 70% (n=35) of cases at Site B had the CCO completed. At Site A, 17.9% (n=5) of the signed CCO included one or more modification to its components while only 8.6% (n=3) of the CCO at Site B were modified. Those two findings may reflect better uptake of the CCO at Site A compared to Site B. Again, this may be attributed to the fact the CCO was initially developed at Site A and then later incorporated into practice at Site B.

In the subsequent paragraphs, I compare the two study sites in terms of the execution of the CCO regarding MV withdrawal and the use of analgesia, sedation, and adjuncts.

Mechanical Ventilation Withdrawal as per the Comfort Care Orders

At Site A, 64.3% (n=18) of patients were weaned to CPAP as a ventilation mode during the WLSM process compared to 32% (n=16) of the cases at Site B. The patient's FiO_2 support was lowered to 0.21 in 71.4% (n=20) of the cases at Site A and in 32% (n=16) of the cases at Site B. Ventilation PEEP was weaned to 10 cm H_2O or less in 67.9% (n=19) of the patients at Site A, and in 42% (n=21) of the cases at Site B. Ventilation Pressure support was reduced to 10 cm H_2O or less in 64.3% (n=18) of the patients at site A, and 34% (n=17) of patients at site B. Finally, a trail of PEEP of 5 cm H_2O and PS of 5 cm H_2O was carried out for 39.3% (n=11) of the patients at Site A, and only 12% (n=6) of the patients at Site B. Accordingly, Site A was more consistent with all components of MV weaning in the CCO.

Analgesia, Sedation, and Adjuncts Use as per the Comfort Care Order Set

In terms of the usage of analgesic IV infusion such hydromorphone or morphine as instructed in the CCO, Site A had 100% (n=28) of its patients receiving an analgesic infusion

during WLSM while at Site B only 80% (n=40) of patients with completed CCO were receiving an analgesic infusion. Bolus analgesia in the form of IV hydromorphone, IV morphine, or subcutaneous (SC) hydromorphone was used in 67.9% (n=19) of cases at Site A compared to 66% (n=33) of the cases at Site B. Site A substituted morphine for hydromorphone in 100% (n=28) of the cases in both infusion and bolus forms, while Site B substituted morphine for hydromorphone in 78% (n=39) of the case in the infusion form, and in 60% (n=30) of the cases in bolus form. The use of IV midazolam infusion as a sedative agent also varied across the two sites, with Site A using it in 89.3% (n=25) of the cases, and Site B using it in 56% (n=28) of the cases. Intravenous or SC boluses of midazolam were used in 64.3% (n=18) of the cases at Site A, and 62% (n=31) of the cases at Site B. In terms of the use of the delivery of analgesia and sedation, continuous infusions were used more frequently at Site A whereas bolus doses were used more often at Site B.

Regarding the use of adjunct medications for symptom management, neither site used any form of atropine or glycopyrrolate as an adjunct for the purpose of secretion management. The only adjunct used in our sample was SC scopolamine which was used more frequently at Site B [30% (n=15) vs 7.1% (n=2) of cases] than at Site A. These variations in practice might be attributed to differences in patient populations or unit practices; however, this would require more investigation to determine. Also, given the differences in patient populations between sites, it is somewhat surprising that Site A (e.g., thoracic surgery, respirology, hematology, and oncology) had lower usage of adjunct agents for secretion management than Site B (e.g., trauma and neurosurgical). Again, further investigation is merited to better understand these differences.

Variation from the Comfort Care Orders

When examining the group of patients for which the CCO was not completed m, it was evident that some aspects of CCO were incorporated into the plan of care while others were not. Aspects related to analgesia and sedation were more likely to be used in the care for those patients than those related to the weaning of MV. For example, 80% (n=12) of those patients received an analgesic infusion of hydromorphone, 46.7% (n=7) received a sedative infusion of midazolam, 46.7% (n=7) received boluses of hydromorphone as needed, and 46.7% (n=7) received doses of midazolam as needed. In contrast, 13.3% (n=2) of those patients were weaned to CPAP as a mode of MV or had PEEP weaned to 10 cm H_2O or less. Further, 6.7% (n=1) of those patients had FiO_2 weaned to 21%, PS weaned to 10 cm H_2O or less, or had a trail of PEEP and PS of 5 cm H_2O attempted. The rationale for why these components of CCO were followed in some cases but not others requires further study. One hypothesis, however, is that in those cases the ICU clinicians chose an individual approach and decide to provide components of the CCO that were appropriate for the patient, such as analgesic and sedative medication, while potentially disregarding other elements (e.g., reducing FiO_2 or changing MV mode). For example, patients for whiomch the CCO was completed in our study, still had some components of CCO not used at all during WLSM. This is perhaps reflective of unit cultures that espouse death and dying as an individualized process and experience whereby standardization is not completely possible or even not desirable. Accordingly, while practice guidelines, corporate policies, and unit order sets are essential steps toward better WLSM and end-of-life care, they remain somewhat inadequate as they fail to fully capture the complexity of WLSM and end-of-life care in the ICU. The issue is that practice guidelines and recommendations describe what ought to be done during end-of-life care and WLSM, yet they provide very little detail regarding

how those recommendations are actualized. Often, it is the ICU nurse's role to orchestrate and implement the WLSM (Long-Sutehall et al., 2011). Ultimately, practice guideline and policies are simply unable to capture and reflect the complexities involved in navigating the end-of-life care and WLSM in the ICU. However, glimpses of those complexities and nuances are often reflected in the ICU nurse's documentation of care. The nursing flowsheet as a principal document and ultimate source of data to create the chart audit extraction tool. This was done purposefully to expand beyond the policies and guideline and explore how the actual processes of WLSM and end-of-life care in the ICU were undertaken by the ICU clinicians, primarily by the ICU nurses. The next section of this chapter describes the ICU nurse's central role in end-of-life care and WLSM.

The Role of the ICU Nurse in End-of-life Care and the Withdrawal of Life-sustaining Measures

While all ICU clinicians play a vital role in the processes of WLSM and end-of-life care, ICU nurses are central to the provision end-of-life care and operationalization of WLSM (Noome et al., 2016; Vanderspank-Wright et al., 2018). The roles and responsibilities of the ICU nurses begin prior to any formal discussion or planned family meeting and extend past the patient's death into bereavement. While not the primary focus of this secondary analysis, the detailed ICU nursing documentation obtained from the ICU flow sheet and translated into the chart audit extraction tool provided an overview of the involvement of the ICU nurses both prior to WLSM and into bereavement.

According to a systematic review of qualitative evidence by Vanderspank-Wright et al. (2018), ICU nurses found the period leading to the family meeting to discuss WLSM to be the most tenuous. This might be because this period entails the navigation of a complex context that

involves the patient's condition, prognosis, comorbidities, wishes, and the family's understanding and wishes (Vanderspank-Wright et al., 2018). During this period, the ICU nurse works to assess the patient's and family's needs and to facilitate and coordinate discussions between and with the patient, the family, and the care providers (Long-Sutehall et al., 201). The ICU nurse also communicates the findings of their assessment to the rest of the ICU care team to help guide care accordingly (Long-Sutehall et al., 2011). The ICU nurse also works to continuously communicate with the family regarding the patient and create a shared understanding of the progressing of patient's condition (Vanderspank-Wright et al., 2018). Documentation regarding family meeting organization, communication around WLSM with family members and the healthcare team was evidenced in the nursing documentation reviewed for the primary study and elements were translated into the chart audit tool – thus indicating congruence with nursing involvement at the study site and the literature.

Once the decision for WLSM has been agreed upon, the nurse works to prepare the patient and the family for the WLSM process (Long-Sutehall et al., 2011; Noome et al., 2016). This entails working to maximize patient comfort and to minimize patient distress using a variety of pharmacological and non-pharmacological interventions (Arbour & Wiegand, 2014; Noome et al., 2016). The ICU nurse also works to ensure the family's readiness for WLSM by providing appropriate education regarding death and dying, how patient care is oriented and organized, the methods of ensuing patient comfort and reducing distress, and the process of WLSM (Arbour & Wiegand, 2014). Evidence from both the chart audit (e.g., use of analgesia and sedation) and again, documentation, indicated that nurses at the study sites engaged in these aspects of care provision specific to end-of-life care and WLSM. Further, the variation in the process of WLSM within the chart audit may provide evidence that the ICU nurse works with the patient and their

family, within the context of the ICU team, to operationalize WLSM in a manner that is aligned with the patient's and the family's wishes and ideals (Long-Sutehall et al., 2011; Noome et al., 2016; Vanderspank-Wright et al., 2018). During this period, the ICU nurse continues to care for and support patients and their families throughout the patient dying process (Noome et al., 2016; Vanderspank-Wright et al., 2018). This includes activities such as preparing the patient and family for the steps of WLSM, explaining what those steps entail, and what to expect during and after those steps (Noome et al, 2016). Throughout this phase, the ICU nurse is constantly assessing the patient's comfort and distress as well as the family's well-being and coping (Noome et al., 2016; Vanderspank-Wright et al., 2018). The goals here are to maintain comfort, minimize distress, and to support the patient's family throughout the WLSM and the dying processes (Noome et al., 2016; Vanderspank-Wright et al., 2018).

Regarding the withdrawal of MV, the exact role of ICU nurse may vary across countries, organizations, and units (Mark et al., 2015). In any scenario, however, the ICU nurse takes on the task of orchestrating WLSM including MV withdrawal (Noome et al. 2016; Vanderspank-Wright et al. 2018). In the case of MV withdrawal, this entails preparing the patient and the family for every step of MV withdrawal including collaborating with other care providers. For example, the ICU nurse may collaborate with the ICU physician, or the ICU RT to wean the patient's respiratory support, and/or extubate the patient (Grandhige et al., 2016; Long-Sutehall et al., 2011). The ICU nurse continues to work to ensure that the patient is comfortable and as pain free as possible using pharmacological and non-pharmacological comfort measures (Noome et al., 2016). Examples of pharmacological comfort measures include the use of continuous intravenous infusion and as needed administration of sedative, analgesic, and symptom specific agents (Noome et al., 2016). Non-pharmacological measures include activities such as

positioning, secretion suctioning, and bathing (Noome et al., 2016). During and after any changes to MV, the ICU nurse assesses the patient's response to those changes, scanning the patient for distress or pain symptoms and responds to it accordingly (Arbour & Wiegand, 2014). Additionally, the ICU nurse also pays a great deal of attention to the family's response and works to explain the changes the family is observing in their loved one (Noome et al., 2016; Vanderspank-Wright et al., 2018). This part of the nurse's role requires the ICU nurse to be highly attuned to the patient's ideals of a good death, often as expressed by their family (Noome et al., 2016). These ideals are often shared during the family meeting preceding WLSM (Long-Sutehall et al., 2011).

If MV is terminated and the patient is extubated, the nurse continues to assess the patient's respiratory comfort and distress and provides care accordingly (Noome et al. 2016). Common areas of concern include gasping, airway obstruction, and respiratory distress (Kompanje et al., 2008; Robert et al., 2020). The nurse works to anticipate and prevent the occurrence of those distressing signs and symptoms and to immediately respond to them when they arise unexpectedly (Vanderspank-Wright et al. 2018). As the patient moves closer toward death, the nurse continues to work to ensure that the patient's family is well prepared for the progression of the dying process and the imminent death of a loved one (Long-Sutehall et al., 2011; Noome et al., 2016).

The ICU nurse's role in WLSM and end-of-life care extends beyond the patient's death. It also entails post-mortem care that is aimed at removing all medical equipment and devices previously attached to the patient (if not removed prior) and the preparation of the patient's body to be transferred to the morgue (Noome et al., 2016; Vanderspank-Wright et al., 2018). The ICU nurse also continues to provide emotional support to the family and provides them with pertinent

information related to the next steps in terms of arranging for funerals or ceremonies (Noome et al., 2016). Further, the ICU nurse's role may extend to involve participating in follow-up interventions after patient death that are aimed at facilitating the family's grieving and coping (Efstathiou et al., 2019; Pattison et al., 2020). While an expanded discussion of bereavement in the ICU is beyond the scope of this thesis, it is imperative that the vital role that the ICU nurses play in supporting the patient's family as they process and cope with the loss of their loved one is highlighted (Efstathiou et al., 2019; Pattison et al., 2020). Family members in the ICU are at a higher risk for developing anxiety and depression (Robert et al., 2017) as well as complicated grief and prolonged grief disorder (Kentish-Barnes et al. 2015; Pattison et al., 2020) after the death of their loved ones. The ICU nurse is constantly assessing the family's condition and needs, working to ensure that the family remains informed regarding the progression of the patient's condition, providing the family with appropriate support, and involving other care providers as needed (e.g., social workers, or spiritual workers) (Noomie et al., 2016, Pattison et al., 2020, Vanderspank-Wright et al., 2018).

Informed by the brief description of the ICU nurse's role in WLSM and end-of-life care, we were able to identify four key time periods in our study that reflected the ICU nurse's role. The first period extends from patient admission to the family meeting for the discussion of WLSM. This period coincides with Coombs "admission with hope of recovery" phase of end-of-life in the ICU (Coombs et al., 2012). The next period is from the WLSM family meeting to the initiation of WLSM, which is reflected in Coombs "transitioning form intervention to end-of-life care" phase (Coombs et al., 2012). The third period begins with the start of WLSM and ends with patient death, while the fourth period is after the patient's death. The last two periods represent Coombs phase of "a controlled death" (Coombs et al., 2012). While the ICU nurse's

role in end-of-life care and WLSM is presented as one that occurs in phases, it is important to highlight that such clear distinction between phases does not exist in the clinical reality. The ICU nurse's engagement in end-of-life care and WLSM is continuous (Noome et al., 2016; Vanderspank-Wright et al., 2018). Further, while the ICU nurse's role has been discussed as a singular role, it is important to highlight that it is rarely ever one nurse that fulfills that role. It is more common for it be a team of multiple nurses that work together over shifts and days to fulfil their role related to end-of-life care and WLSM in the ICU (Noome et al., 2016; Vanderspank-Wright et al. 2018)

Implications for Critical Care Nursing Practice, Research, and Education

Our examination of MV withdrawal methods makes evident the contextuality and complexity of WLSM and end-of-life in the ICU. It highlights that WLSM and end-of-life care in the ICU should be approached as unique and that care ought to be planned and delivered accordingly. ICU clinicians should strive to understand the needs of each patient and work to provide end-of-life care that is aligned with those needs. When withdrawing MV, ICU clinicians should consider patient's pathophysiology as well as the patient's wishes in choosing the method for MV withdrawal. Accordingly, all ICU clinicians should be provided with frequent training and education regarding method of WLSM. Further research is required to explore the various methods of WLSM, the potential advantages and disadvantages to those methods, and the appropriateness and suitability of those methods. Additionally, our discussion brings to light the high levels of mental, physical, and emotional involvement required in the ICU nurse's role during WLSM and end-of-life care. It emphasizes that WLSM and end-of-life care should not be viewed as a "lighter" or "less complex" workload than caring for critically ill patients for whom

the goal of care remains curative. Accordingly, ICU patients undergoing WLSM, and receiving end-of-life care should receive nursing care in similar ratios to those who are critically ill.

Further, end-of-life care and WLSM in the ICU can benefit greatly from the incorporation of an expert role within the ICU care team, namely an Advanced Practice Nurse (APN) (Kalowes, 2015; O'Mahony et al., 2017). In the Pan-Canadian Framework for Advanced Practice Nursing, the Canadian Nurses Association (CNA) (2019) defined the APN role as "umbrella term for registered nurses (RNs) and nurse practitioners (NPs) who integrate graduate nursing educational preparation with in-depth, specialized clinical nursing knowledge and expertise in complex decision-making to meet the health needs of individuals, families, groups, communities and populations" (p. 13). Below is a brief description of how the competencies of the APN role would benefit end-of-life care and WLSM in the ICU based on the discussion provided by Stokes (2018).

Direct Care

The ICU APN may be involved directly in end-of-life care and WLSM in any case but particularly the more complicated patient situations. The APN can be involved in assessing the patient and the family's needs and perceptions, facilitating end-of-life and WLSM discussions, designing care plans that are tailored to the patient's and family's specific context, working collaboratively to implement those plans, and following up with patient's families afterword. Specific to MV withdrawal, the APN can work with the care team to evaluate the patient's and family's context and the appropriateness of TW or TE for that context. The APN can also, provide coaching to the provider involved in the patient care and role model quality end-of-life care.

Leadership

Within this competency, the ICU APN can work to assess and address the learning needs of the ICU nurses, as well as other care providers, related to end-of-life care and WLSM in the ICU. The APN can also work to drive unit and organizational changes toward better end-of-life care. Example of such changes include the implementation of policies that encourage individualization of end-of-life care and WLSM including MV withdrawal and allow for modifications throughout those processes.

Consultation and Collaboration

The ICU APN can serve as a resource role for the ICU as well as for the entire institution. In doing so, the APN can help support quality end-of-life care not only within the ICU but within the entire institution. Within the ICU, the APN remains an expert clinician that nurses and other care providers are able to consult for guidance and direction in any cases. The APN will also collaborate with other team members to ensure that the care provided to the patients and their families is comprehensive and holistic.

Education

Another area for the ICU APN is to educate all ICU clinicians, as well as the patients and their families, regarding the core values and principles of quality end-of-life care and WLSM in the ICU, as well as the possible methods of MV withdrawal and their applications. The APN can do so both through teaching dedicated sessions or events, as well as, through clinical practice and role modeling. Further, The APN can play a role in teaching and training new staff members and help support their integration within the unit.

Research

The ICU APN possesses the required knowledge and skills to generate, synthesize, critique, and apply evidence (CNA, 2019). Accordingly, the APN within the ICU can conduct various types of research to explore end-of-life care and WLSM within the ICU, analyze and evaluate existing evidence regarding those areas, and work to incorporate relevant evidence into the unit practice. By doing so, the APN contributes to the improvement of end-of-life care and WLSM, not only within their respective ICU, but also nationally, and internationally.

Limitations

Our study has some limitations that I would like to highlight. First, our sample was relatively small, and Site B composed 64.1% of the sample (n=50), while Site A only included 28 participants. This may have contributed to the practices at Site B being more predominant in our sample and overshadowing the practices at Site A. Accordingly, we presented our findings across sites as well as across groups to help reflect the practices of each site and ensure fair representation.

The second limitation is related to the source of the data in our study. Being a chart audit study, the quality of our data is determined by the quality of the documentation in the patients' medical records. Accordingly, some variables may have been misrepresented due to inaccurate or incomplete documentation. Further, it is not possible to objectively quantify some variables such as the presence of respiratory distress or upper airway obstruction, instead, it is only possible to report whether those variables were documented in the patients' charts. Consequently, some incidents of respiratory distress and upper airway obstruction might not have been captured. Further, with no consistent measure of distress or obstruction,

documentation was reflective of the subjective interpretation of the care provider at the bedside – namely, the ICU nurse.

Finally, while our findings maybe relevant and applicable in some contexts, they may be irrelevant in others. Accordingly, it is the onus of the reader to evaluate the applicability of our findings within their practice context. Further, it is important to remember that our study was descriptive in design. Tests were not performed to evaluate the statistical significance of any difference across our study groups. Our data, findings, and discussions should be interpreted accordingly.

Conclusion

In this thesis, the practices and process of MV withdrawal within the context of the ICU were explored. TW and TE as the two methods of MV withdrawal described and compared at two sites. The use of the standardized WLSM order set that is employed in the study sites was also explored. The secondary analysis supports the need for customizable context-sensitive end-of-life care and WLSM processes and discourages standardization. Policies and guidelines, while fundamental, should not be viewed as all that is needed for quality end-of-life care. Further research in imperative to better understand and explore the complexities and nuances of WLSM and end-of-life care in the ICU. The pivotal role of the ICU nurse in WLSM and the care required is highlighted.

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Appendix A

Comfort Care Orders for the Withdrawal of Life Support

The intent is to enable a patient who has been determined to be terminal to achieve death with dignity and to alleviate or prevent pain and suffering during the withdrawal process. Sedative and analgesics should be given in sufficient doses and at appropriate intervals to ensure patient comfort. Although respiratory and hemodynamic depression may result from giving sedatives and analgesics, these effects are acceptable if relief of pain and suffering is the primary objective

1. Complete life support checklist
2. Titrate to comfort:
    a. Morphine (typically changed to Hydromorphone): start at present rate or at (generally 0.2 mg/hr), bolus (generally 0.4 mg prn), and adjust infusion prn.
    b. Midazolam: start at present rate or at (generally 2 mg/hr), bolus (generally 2-4 mg prn), and adjust infusion prn.
    c. No dosage limits: increase rate at any signs of distress:
        i. Grimacing, clutching, gasping, restlessness, diaphoresis
        ii. Respiratory rate > 24b/min, nasal flaring, accessory muscle use
        iii. Heart rate increase > 20%, SBP > 20%
3. Assess family's perception of patient's comfort level q 1h + prn, and their coping
4. Liberalize visitation, transfer to private room if available
5. Minimal intravenous fluids
6. Enteral feeding may continue if requested by the family
7. Begin oral nutrition if requested by the patient or the family
8. Stop all investigation, drugs except sedatives, etc. AND wean vasopressors by 50% q5mins until discontinued.

9. Remove all devices not necessary for comfort when possible and at discretion of RN/MD/family (eg catheters, NG tubes, vascular cannulae, monitors, restraints, SCDs, etc)
10. Wean down FiO2 to 0.21, PEEP to 10 cm H2O, PS 10 cm H2O, Rate to CPAP from existing mode of ventilation.
    a. Make changes q 5-10 mins and observe patient for any signs of distress:
        i. Grimacing, clutching, gasping, restlessness, diaphoresis
        ii. Respiratory rate > 24b/min, nasal flaring, accessory muscle use
        iii. Heart rate increase > 20%, SBP > 20%
    b. If distress apparent:
        i. Increase sedatives
        ii. Increase ventilation until sedatives are effectives
        iii. Scopolamine 0.3-0.6 mg IM SC, q6h PRN for secretions
    c. If no distress is apparent
        i. Do not increase sedatives, proceed to 5/5 trail, trail 5/5 trail for 10 mins
        ii. If satisfactory, extubate +/- oral airway prn, unless family or caregivers believe patient would be less comfortable (use T piece instead of extubation)
        iii. In unsatisfactory, increase sedation and try again)
11. Disconnect from electric monitor and discontinue vital sings measurements when off the ventilator.
12. NO chest compression or other resuscitation
13. Clinical rather than electrical definition of death (apnea, no pulse, etc)

Appendix B

Chart Audit Extraction Tool

Table 1		
Study Unique ID:	**ICU Service Date:** DD/MM/YYYY	
Age: 00.00 Y	**Sex:** Male/Female/Other_____	
Primary reason for admission/most responsible diagnosis:		
Secondary diagnosis (if applicable):		
<u>Past Medical History:</u> **Neurological:** **Cardiovascular:** **Respiratory:** **Gastrointestinal:** **Genitourinary:** **Hematology:** **Endocrine:** **Oncology:** **Miscellaneous:** **Others:**		
Pacemaker: Yes/No	**Type:**	**Internal Defibrillator:** Yes/No
Allergies:		
Current Admission Issues:		
<u>1)</u>	**<u>2)</u>**	
<u>3)</u>	**<u>4)</u>**	
<u>5)</u>	**<u>6)</u>**	
Category of Care Documented on Admission: Yes/No	**Initial Care Category:**	
Category Details:		
Was Charlson Comorbidity Index (CCI) Score documented: Yes/No		
Was APACHE Score documented: Yes/No		

Table 2	
Date and Time of Death: DD/MM/YYYY HH:MM	
Cause of Death	**Duration**
Immediate:	
Morbid:	
Other:	

Table 3
Was Trillium Gift of Life notified of imminent death or post mortem? Yes/No
Next of Kin:

Table 4
Date Category of Goals of Care Documentation Changed to Category 2 or 3: DD/MM/YYYY HH:MM
Details (if present):

Table 5
SPO 82 11/2004 "Comfort Care Orders for Withdrawal of Life Support" Completed: Yes/No
Date and Time of SPO 82 11/2004 Completion: DD/MM/YYYY HH:MM
Modifications To SPO 82 11/2004: Yes/No
Details:
If no, Is there a "Multiple Organ and tissue donor – Phys. Orders" file? Yes/No , DD/MM/YY HH:MM
If the answer is Yes to either of the two questions, then proceed to table 7. If the answer is no to both questions, please complete table 6 then stop data collection from this chart.

Table 6
Is this a non-WLSM case? Yes/No
Were comfort measures rejected by the patient or the family? Yes/No/Not documented
What was the medical management plan?

Table 7
Family Meeting/Conference Documented (most immediate to WLSM): Yes/No
Date of Family Meeting/Conference: DD/MM/YYYY HH:MM
Was the patient capable of making their own decision? Yes/No
Was the patient present (i.e. meeting at bedside)? Yes/No
If not, who is legal decision maker for patient? (Spouse, Immediate Family Member, Other)
Which multidisciplinary team members were present in family meeting (e.g. SW, Spiritual Care, RN, MD, RT, Physio, Other)?
Which family members were present in family meeting?
Was plan of care regarding withdrawal of treatment relayed to the patient and family members accordingly? Yes/No
Family members present at time of death: Yes/No/Not documented

Table 8	
Patient Last Recorded Weight: 000.0 Kg	
Isolation Precautions in Place During Withdrawal of Treatment: Yes/No	
Type of Isolation Precaution:	
Date and Time of Trillium Gift of Life notification: DD/MM/YYYY HH:MM □ Not documented	
Organ and Tissue Donation: Yes/No	**Donation after Cardiocirculatory Death (DCD):** Yes/No

Neurologic Determination of Death (NDD) Donation: Yes/No	
Date and Time of Brain Death Declaration: DD/MM/YYYY HH:MM	
Was the patient in the Prone position? Yes/No	
If yes, when was patient placed in supine position? DD/MM/YYYY HH:MM	
Pacemaker Discontinued: Yes/No	**Date and Time:** DD/MM HH:MM
Internal Defibrillator Discontinued: Yes/No	**Date and Time:** DD/MM HH:MM

Non-Pharmacological Care during WLSM

Table 9
Was non-pharmacological care such as (suctioning, repositioning, skin care, eye care, mouth care, and bathing) documented? Yes/no

Airway and Ventilation

Table 10	
Invasive Ventilation Type:	
ETT Insertion: DD/MM/YYYY HH:MM	**ETT Size:** 0.0 mm
Trach Insertion: DD/MM/YYYY HH:MM	**Trach Inner Cannula Size:** 0.0 mm

Table 11	
Initial Ventilation Mode: **Invasive:** 1. SIMV (Synchronized Intermittent-Mandatory Ventilation) 2. CPAP/PSV (Pressure Support Ventilation) 3. A/C (Assist-Control Ventilation) 4. CMV (Controlled Mechanical Ventilation) 4. PCV (Pressure-Controlled Ventilation) 6. Other (please specify) _____ **Non-Invasive:** 7. BIPAP (Date and time started DD/MM HH:MM) 8. Supplementary O_2, Specify _____ 9. Other (please specify) _____	
Initial FiO_2: 00 **%** or 00 L/min	
Initial setting:	
Positive End-Expiratory Pressure (PEEP):	Set Volume (Vol):
Pressure Support (PS):	Set Rate (R):
Driving Pressure (DP):	Other Parameters:

Table 12		
Ventilation Weaning: Changes starting at 2400 and after are entered under the next day.		
Date	**Time**	**Changes**

Table 13
Documentation of Respiratory Distress: Yes/No
Evidence of Upper Airway Obstruction after extubation: Yes/No/Not intubated/Trached/Not extubated

Medications

Coding Guide:
S: Start of Comfort measures
N: Nurse judgement (such as before providing care)
O: Ordered by physician
P: Pain
F: Family or patient request
V: Corresponds to ventilation parameter change
R: Respiratory Symptoms
T: Any other reasons
Ø: No rationale documented

Continuous infusions:
Only record changes to infusion rate. The first empty line on the flowsheet represents the discontinuation time (off). If multiple changes are done in one hour, please repeat the hour as in the example below. For medications present prior to WLSM, please start recording the rate from 1 hour prior to WLSM. For medications added for comfort, start recording from the time of initiation. For medications administered using a CADD pump, please indicate so next to the medication name. ***See example below.***

Medication and rate units	**Started @ (If not present prior to WLSM)**	12	DD	DD	DD	DD	13	DD	DD	13	14	DD	DD	DD	DD	DD
		12	16	20	22	22	04	08	14	22	01	HH	HH	HH	HH	HH
Midazolam mg/hr	11:15 12/06	1	2	4	6	7	8	10	12	14	off					
Documented rationale		S	N	O	P	F	T	Ø	V	R						
Medication and rate units	**Started @ (If not present prior to WLSM)**	12	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD
		11	12	14	18	22	23	HH	HH	HH	HH	HH	HH	HH	HH	HH
Propofol mg/kg/hr	Pre WLSM	3	2.5	2	1	0.5	off									
Documented rationale																
Medication and rate units	**Started @ (If not present prior to WLSM)**	12	DD	13	DD	DD	14	DD	DD	DD	DD	DD	DD	DD	DD	DD
		11	16	8	18	22	01	HH	HH	HH	HH	HH	HH	HH	HH	HH
Hydromorphone **CADD** mcg/hr	Pre WLSM	200	400	600	800	900	off									
Documented rationale			S	V	T	N										

Table 14

Comfort Measures Initiation Date and Time: DD/MM/YYYY HH:MM
WLSM Initiation Date and Time: DD/MM/YYYY HH:MM

Medication and rate units	**Started @ (If not present prior to WLSM)**	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD
		HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH
Medication and rate units	**Started @ (If not present prior to WLSM)**	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD
		HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH
Medication and rate units	**Started @ (If not present prior to WLSM)**	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD
		HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH
Medication and rate units	**Started @ (If not present prior to WLSM)**	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD
		HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH
Medication and rate units	**Started @ (If not present prior to WLSM)**	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD	DD
		HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH	HH

Bolus medications:

Record all boluses from the time of WLSM initiation***. Follow the example below***, use the same format for the documented rationale

Medication	Dose	Doses	Date	Times of administration	Total
Midazolam	0.5mg	6	20/01	1010 N, 1108 O, 1247 F, 1355 R, 1820 Ø, 2210 T	3
	2 mg	2	20/01	0201 R, 2355 R	4
	2 mg	2	21/01	0750 T, 1500 N	4
				Medication Total	11 mg

Table 15					
Medication	**Dose**	**# Doses**	**Date**	**Times of administration**	**Total**

Table 16					
Were analgesics (e.g., Acetaminophen, Ibuprofen, Tylenol 2 or 3) given by any of the following routes (PO/PR/NG/KF) following the initiation of WLSM and until the time of death? Yes/No					
Medication					
Total amount given (include unit)					

Table 17					
Is there evidence of other pharmacological management used during WLSM (e.g., scopolamine, atropine, glycopyrrolate, nebulized morphine, nebulized epinephrine) given by any of the following routes (SC/PO/PR/NG/KF/Neb) following the initiation of WLSM and until the time of death? Yes/No					
Medication					
Total amount given (include unit)					