Withdrawal of Life-Sustaining Measures

Canadian Critical Care Society Guideline Implementation and Quality Assurance Workshop

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Toronto, Ontario

Canadian Blood Services
it's in you to give

CCCS
CANADIAN CRITICAL CARE SOCIETY

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Acknowledgements

We wish to honor and acknowledge Mr. Michael Kampen, Mr. Francis Moran and Ms. Alison Morsley, our family representatives, for generously sharing their time, insights and personal experiences. Their collective presence and participation inspired and focused us - constantly compelling participants to improve end-oflife care for all Canadians.

This report provides an overview of the Withdrawal of Life-Sustaining Measures Guideline Implementation and Quality Assurance workshop, and a summary of participant recommendations in response to draft implementation tools. The workshop was based on the collaborative input of a broad range of stakeholders, family partners and experts with formal representation from Canadian Blood Services, the Canadian Critical Care Society, the Canadian Association of Critical Care Nurses, the Canadian Association of Palliative Care Physicians and the Canadian Conference of Chief Coroners and Chief Medical Examiners. The Steering Committee would like to thank Canadian Blood Services and the Canadian Critical Care Society for their partnership of this initiative, as well as all participants who helped in the creation of these recommendations. (Refer to Appendix C: *Workshop Participants and Affiliations*).

This workshop to develop implementation tools and strategies to support programs in implementation of the Canadian Critical Care Society Guidelines for the Withdrawal of Life-Sustaining Measures was a collaborative effort between Canadian Blood Services and the Canadian Critical Care Society (http://www.canadiancriticalcare.org). Production of this report has been made possible through financial contributions from Health Canada and the provincial and territorial governments. The views expressed herein do not necessarily represent those of the federal, provincial or territorial governments.

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Foreword

Canadians support donation. Polling indicates overwhelming support for organ and tissue donation.[1] Our first priority for the majority of our patients is to save their life while providing comfort and symptom relief in the process. In some patients, we cannot save their life and families (in rare circumstances, patients) make decisions to shift their first priority to symptom relief and comfort. In this transition of priorities, we must provide the opportunity for deceased donation.

It has been over 10 years since the first case of controlled donation after circulatory determination of death (cDCDD) in Canada. Since that time cDCDD has become embedded in the culture of critical care across the country. In our view, offering the opportunity for cDCDD is an expectation of critical care providers at end-of-life (EOL). As thoughtful scientists and empathetic clinicians reflect on the growing experience in this field, we have gained a better understanding of the challenges and opportunities associated with this form of deceased donation. Careful decisions are made regarding the best treatment for patients based on their prior expressed wishes, values and beliefs. While high quality EOL care includes organ donation, only a small proportion of patients undergoing withdrawal of life-sustaining measures (WLSM) may be eligible for cDCDD. Expert EOL care is essential; irrespective of the medical eligibility for donation or the choice to proceed to deceased donation.

To support best practice and standardization in the management of the dying process, the Canadian Critical Care Society (CCCS) supported the collaboration of health professionals in the development and publication of *Guidelines for the Withdrawal of Life-Sustaining Measures*.[2] This partnership continues with Canadian Blood Services, the Canadian Critical Care Society, the Canadian Association of Critical Care Nurses, the Canadian Society of Palliative Care Physicians, intensivists, organ donation organizations, social workers, respiratory therapists, spiritual care, ethicists and family partners coming together for a two day workshop aimed at translating the CCCS WLSM Guidelines into a framework for practice.

Our work is framed by expert care at the EOL where: *'Organ and tissue donation is an essential component of high quality EOL care, and it is essential that EOL care be of high quality in organ and tissue donation'*.

This workshop set out to develop guiding principles for the application of the CCCS guidelines in WLSM and implementation tools to support the incorporation of these guidelines into clinical practice. We must ensure the principles of the guidelines are applied independent of donation opportunities while acknowledging and accepting that preserving the opportunity for deceased donation may require accepted variations to process. In addition, we hope to provide a quality assurance framework to support the hospital(system)-based and case-based audit of compliance with CCCS WLSM guidelines and to support ongoing process improvement.

As we move forth, we must understand, address and be open to the variety of tensions and perspectives of care providers at EOL, in WLSM and in deceased donation. The health care system – and in particular, the donation system embedded within it – is based on public trust. When deceased donation follows

WLSM, we know that opportunities for bias and influence exist, both for and against deceased donation. We understand there are ethical and legal considerations. We question 'what is permissible' for us to do at the bedside and 'what is required of us?' We must focus on the needs, wants and interests of the patient and the family.

The challenge for us is to ensure deceased donation does not conflict with how we define expert and high quality EOL, but rather elevates the expectations.

Dr. Andrew Healey, Chair

Withdrawal of Life-Sustaining Measures Guideline Implementation and Quality Assurance Workshop

Executive Summary

Workshop purpose and objectives

As Canadian experience with controlled donation after circulatory determination of death (cDCDD) matured, it became evident varying practices of the withdrawal of life-sustaining measures (WLSM) have emerged. Without standardization of practice, there could be perceptions of undue influence on consent and donation with WLSM. In response, the Canadian Critical Care Society (CCCS) undertook a review of the published literature and developed an evidence-based leading practice, Guidelines for the Withdrawal of Life-Sustaining Measures, published in 2016, to improve the quality of end-of-life (EOL) care provided in intensive care units (ICUs).

Recognizing a need for broader implementation and uptake of these guidelines, Canadian Blood Services and the CCCS partnered to develop tools and a quality assurance process to support the implementation of the CCCS WLSM guidelines in critical care programs across Canada - an important step in translating these guidelines into clinical practice at the bedside and ensuring the consistent application of WLSM practices independent of the opportunity for donation.

This initiative focused on actions from the decision to WLSM until death. The decision process related to prognostication and the decision to WLSM were out of scope.

A collaborative workshop brought together family partners and Canadian leaders in donation, critical care and palliative care to meet the following objectives:

- develop a set of guiding principles for the application of the CCCS WLSM guidelines;
- develop tools to support the implementation of the CCCS WLSM guidelines;
- develop tools to support quality assurance in WLSM;
- develop a WLSM organizational policy template;
- identify potential implementation challenges relating to WLSM; and
- identify research opportunities and priorities to advance improvements in WLSM and organ and tissue donation in EOL care.

A planning committee was established December 2016 to identify workshop objectives, scope, develop background documents and establish the workshop process. This resulted in reviews of medical literature and an environmental scan of critical care and donation program resources which informed the development of draft tools for consideration and revision by workshop participants.

Thirty-eight participants including family partners and health care professionals in critical care medicine, palliative care, organ and tissue donation, bioethics, nursing, respiratory therapy, social work, spiritual care, bioethics and death investigation met for informative presentations, challenging open discussions, and review and revision of implementation tools over two days. Family partners were prepared in advance of the workshop and identified as fully contributing participants.

A comprehensive background package was provided to participants who were asked to review and familiarize themselves with the CCCS WLSM guidelines in advance of the workshop. Presentations focused on the development and content of the CCCS WLSM guidelines, implementation and quality assurance tools, unique experiences from family partners to inform clinical care and the coroner provided perspectives on quality assurance in WLSM and guiding principles for donation following WLSM. Participants revised and approved a statement of principles and reviewed the implementation and quality assurance tools to identify strengths, gaps, areas of concern and recommended revisions.

Summary of workshop outputs

1. **Statement of guiding principles for WLSM and DCD**

   The principles of expert inter-professional critical care must foster a seamless transition into end-of-life care. It is imperative that end-of-life care in the critically ill be of the highest quality, in all circumstances, including that of organ and tissue donation.

   High quality end-of-life care:

   - maintains dignity, respect and compassion;
   - explores the wishes and voices of the patient and family/substitute decision maker (SDM);
   - respects cultural, spiritual values and observances;
   - continues to support and partner with patients, families/SDM and health care team members throughout the death experience;
   - is consistent with guidelines for WLSM;
   - focuses on alleviating pain, distress and providing comfort;
   - adheres to the existing medicolegal framework that includes respect for the dead donor rule and precludes intentional hastening of death (notwithstanding medical assistance in dying legislation);
   - avoids unnecessary prolongation of the dying process; and
   - preserves the opportunity to donate organs and tissues.

   These principles of person-centered care in the intensive care unit must be maintained throughout conversations, assessments and procedures involved in organ and tissue donation. While it is acknowledged that individual WLSM plans may be subject to variability in response to patient/family/SDM priorities, these principles of high quality care must be maintained.

   We are collaborating nationally to ensure consistency in application of guiding principles, methods of assessment, patient and family support, and program evaluation at all sites involved in organ and tissue donation within Canada.

2. **Implementation tools**
   - order set
   - checklist
   - documentation tool
   - family information package

3. **Quality assurance tools**
   - system audit tool
   - case audit tool
4. **WLSM organizational policy template**
5. **Implementation considerations**
6. **Research agenda**

The planning committee will develop a comprehensive communication strategy to support knowledge translation, adoption and incorporation of the implementation and quality assurance tools into critical care practices. Part of this strategy will involve dissemination through the Canadian Blood Services Professional Education website, the Deceased Donation Advisory Committee, the Donation and Transplant Administrators Advisory Committee, the Donation Physician Network and publications and presentations in appropriate peer venues. In addition, the planning committee will consider mechanisms through which implementation considerations and research opportunities can be shared with relevant stakeholders more broadly.

Workshop overview

Background

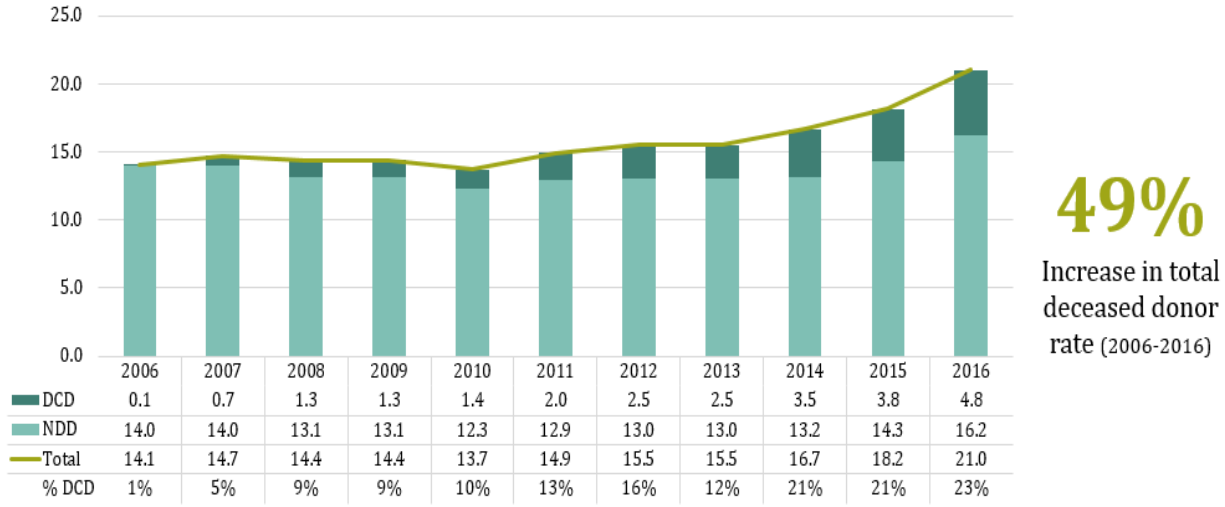
The Canadian donation and transplantation community represents a complex collaboration of 10 provincial donation organizations, 80 transplant programs, 286 ICUs, Canadian Blood Services, the Canadian Critical Care Society, the Canadian Association of Critical Care Nurses, the Canadian Society of Palliative Care Physicians and other professional and patient advocacy organizations. The community has focused on a number of donation strategies including engaging the ICU community in donation and creating a culture of ownership, the professionalization of donation services with the implementation of nurse coordinators and donation physicians, research to inform health policy and the development of national evidence-based leading practice guidelines for each component of the donation process. Since 2003 Canadian Blood Services has facilitated the development of 18 deceased donation leading practice guidelines.

Canadian Blood Services and CCCS collaboratively developed the cDCDD national practice guidelines, published in the Canadian Medical Association Journal in 2006. Initially there was contention around adopting cDCDD practice due to a variety of medical and ethical issues. One challenge focused on the donation opportunity and consent discussions arising prior to death, rather than after death, as in neurological determination of death (NDD). Other challenges included: concern surrounding pre-mortem interventions; decisions and actions around EOL care which may be influenced by the cDCDD opportunity; death determination; professional knowledge; logistics and resourcing; and access to surgical recovery teams. These challenges were addressed systematically and cDCDD was implemented progressively across Canada.

cDCDD accounts for the largest rise (48 per cent) in deceased donation of the past decade and currently 23 per cent of all organ donations are after circulatory determination of death; with over 1600 transplants occurring from 800 cDCDD donors since 2006.[3] However, adoption of cDCDD and the proportion of donation following cDCDD varies across Canada. The Trillium Gift of Life Network in Ontario was an early adopter of cDCDD and has the largest cumulative experience in Canada with cDCDD accounting for more than 30 per cent of deceased donation activity in that province.

It is important to note the number of patients who WLSM and have the potential for cDCDD, but who do not die within the timeframe for donation is significant. Depending on the system, donation is not realized in up to 30 per cent of patients for whom WLSM occurs with surgical teams on standby.

Figure 1: Deceased donors in Canada, 2006-2016 (DMP)[3]

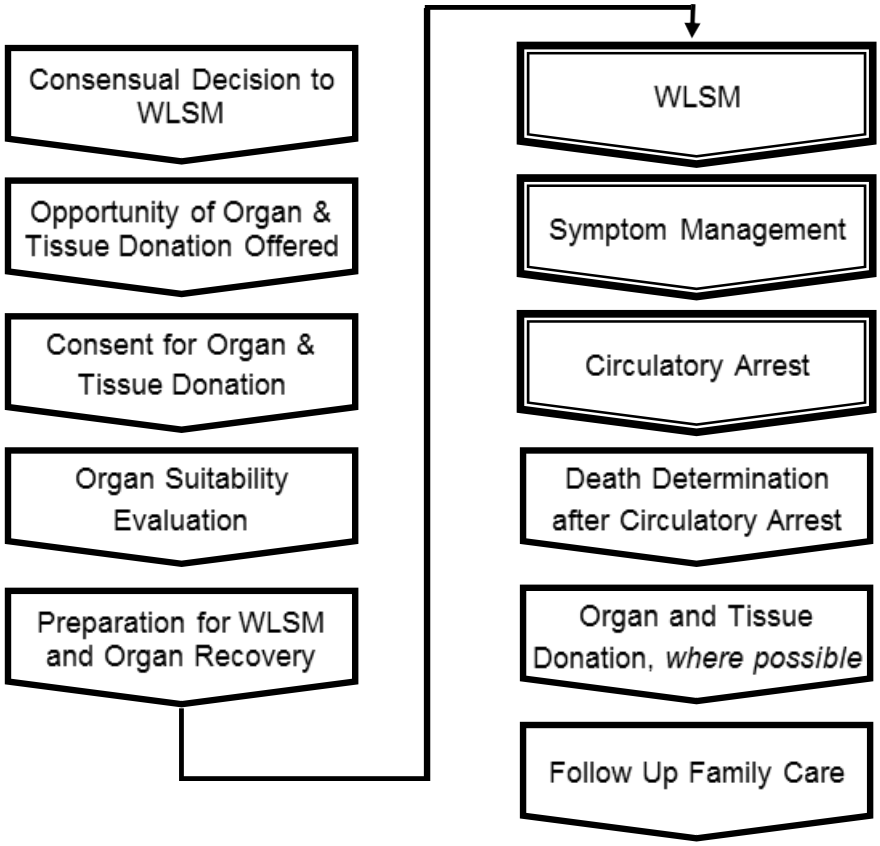


A study of deaths in 15 Canadian ICUs indicated 53 per cent of patients were involved the WLSM; specifically, mechanical ventilation.[4] Literature indicates that WLSM practices widely vary between institutions and countries.[5] Without standardized practice there could be perceptions of undue influence on consent and donation with the WLSM. In response, the CCCS undertook a review of the published literature and developed evidence-based leading practices. The CCCS Guidelines for the Withdrawal of Life-Sustaining Measures were published in 2016.[2] The goal of the guideline development group was to improve the quality and consistency of EOL care provided in ICUs.[2] Guideline development included a focus on medical practice, patient comfort, supporting the needs of the family and staff, ethics, legal, the dying process and ensuring competing interests such as bed availability or organ donation do not impact the decision to WLSM or the process.

Preliminary results of a recent study where 27 donor families were interviewed demonstrates that informational needs of patients and families are not always being met. Many donor families were unable to process verbal information and suggested information, in written form, would allow them to review and process the information - improving overall communication. Positive experiences were noted by donor families who felt they were part of the health care team; for example, when donor coordinators kept donor families informed of the donation process and shared what tests they were performing and why.

Figure 2 outlines the cDCDD clinical process. The shaded boxes refer to segments of the clinical processes of focus in this report, to assure quality from the first step of WLSM to death.

Figure 2: cDCDD clinical process



Workshop purpose and objectives

Translating the 2016 CCCS WLSM guidelines into clinical practice requires an investment in implementation strategies to assure quality around EOL care and cDCDD. Recognizing a need for broader implementation and uptake of the CCCS WLSM guidelines, as well as the need to improve care for families, Canadian Blood Services and the CCCS partnered to develop tools and a quality assurance process to support the implementation of the CCCS WLSM guidelines in all critical care programs across Canada with a focus on hospitals providing cDCDD.

A planning committee was organized in December 2016 to identify strategy, objectives, scope, background documents and establish the workshop process. As a result, medical literature reviews and an environmental scan of critical care and donation program resources were conducted to inform the development of draft tools for consideration and revision by workshop participants.

Planning committee

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Corporate Division Head and Medical Director, Critical Care, William Osler Health System
Associate Clinical Professor, Department of Medicine, McMaster University

Amber Appleby
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Dr. James Downar
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Chair, Ethical Affairs Committee, Canadian Critical Care Society, representative Canadian Society of Palliative Care Physicians

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Division of Pediatric Critical Care Montreal Children's Hospital McGill University Health Centre and Research Institute, Professor of Pediatrics, McGill University
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Workshop objectives

The workshop objectives were to:

- develop a set of guiding principles for the application of the CCCS WLSM guidelines;
- develop tools to support the implementation of the guidelines;
  - order set
  - checklist
  - documentation tool
  - family information package
- develop tools to support quality assurance in WLSM;
  - system audit
  - case audit
- develop a WLSM organizational policy template;
- identify potential implementation challenges relating to WLSM; and

- identify research opportunities and priorities to advance improvements in WLSM and organ and tissue donation in EOL care.

In Scope

- adult and pediatric ICU patients in whom the decision to WLSM has been reached between patient/family members/SDM and the health care team
- clinical care process from first step of WLSM to death;
- all hospitals, with a focus to those supporting cDCDD;
- tools to support implementation and quality assurance of CCCS WLSM guidelines and management of EOL care, including but are not limited to:
  - family engagement and support;
  - WLSM (respiration, cardiovascular, other)
  - monitoring and documentation;
  - sedation and analgesia; and
  - other palliative care interventions.

Out of Scope

- prognostication and the decision to WLSM
- donor management
- medical assistance in dying

Considerations

While this initiative will address WLSM in all hospitals, focus will be placed on ensuring guideline implementation and quality assurance tools for hospitals where cDCDD occurs. Through this process we sought to ensure the framework for quality improvement is sufficiently flexible to adapt to different environments and recognize the unique needs and practices of different regions, programs and health care professionals. Critical care and organ donation and transplantation (ODT) professionals will continue to make collaborative decisions and choices with patients and their families to optimize and personalize patient-centered EOL care in the context of donation. Implementation and quality assurance recommendations pertaining to WLSM and knowledge translation tools will require implementation strategies that recognize the complex diversity of critical care practice.

Background documents

The following documents were pre-circulated to all workshop participants:

- CCCS WLSM Guidelines[6]
- *How is life support withdrawn in intensive care units: A narrative review*[5]
  Dr. Delaney, lead author of the literature review, undertook an update to identify and assess relevant literature published up until December 2016, which was not captured in the original review. An additional 63 publications were identified and reviewed. Refer to *Appendix E*
- Canadian cDCDD Guidelines[7]
- Donation Physician Ethics Guide[8]

The following environmental scan was commissioned by the planning committee to inform the development of the implementation tools refined at the workshop.

Environmental Scan of WLSM resources to support patients, family members and clinical staff (March 2017)

Dr. Downar and Dr. Spring conducted an environmental scan to identify what resources currently exist to support patients, family members and clinical staff. Examples included order sets, policies, guidelines, educational materials, environmental aids, checklists, post-case debriefing guides, quality assurance processes and documentation tools for the clinical process of WLSM and the performance of cDCDD. The request for materials was sent to 123 unique stakeholders via email. Stakeholders included Canadian critical care physicians, donation physicians, Canadian organ donation organizations and 16 members of international organ donation organizations. In total, 21 responses (17.1%) were received with 3 respondents indicating they did not have any relevant resources available at their center. The compiled summary of evidence was used by planning committee members to inform the development of draft tools. Prior to the workshop, Dr. Downar and Dr. Spring reviewed the draft tools to identify additional areas of alignment and potential gaps in relation to content gathered during the environmental scan.

Participants and workshop process

The workshop involved 38 participants (refer to Appendix C: *Workshop participants and affiliations)* with pan-Canadian representation of leaders in organ donation, critical care, family partners, Canadian Blood Services, Canadian Critical Care Society (CCCS), Canadian Association of Critical Care Nurses (CACCN), Canadian Society of Palliative Care Physicians (CSPCP) and experts from front line nursing, respiratory care, social work, spiritual care, death investigation and bioethics. To promote interaction and fulsome discussion, participants were assigned seating to promote interdisciplinary representation at discussion tables. Participants met for informative presentations, challenging discussions, and review and revision of implementation tools.

The experiential knowledge of patients and family members provides essential perspectives and informs on positive and negative experiences of health care delivery and communication including diagnosis, treatments, follow up and quality EOL care. They inform on needs which have not been met, preferences on how those needs can be met and on their involvement in decision making. For this workshop three patient family partners were engaged to inform discussions. Two partners were full participants in the workshop and a third partner, who was unable to attend, provided a “twitter feed” documenting in real time his families experience of the WLSM and deceased donation. Members of the planning committee met with family partners prior to the workshop to prepare them and provided support as needed. Family partners participated fully in discussions, shared their individual stories at the beginning of the workshop and their perspectives on the work done at the close of the workshop.

Family members acknowledged different perspectives. While health care providers may see care as very separate components (diagnosis and treatment, critical care, EOL care decisions, WLSM, and donation), family members do not experience care in this way; they experience this as one continuous event. Family members suggested the provision of donation information earlier in the process may be helpful. One family member offered a perspective for consideration: families are not visitors to the hospital, rather the

health care teams are visitors welcomed into their family and their most intimate life experiences of loss. Families are part of the care team and critical to the decision-making processes; the impact of their experience in WLSM and donation will be carried with them for the rest of their lives.

A comprehensive background package was provided to participants prior to the workshop and participants were asked to review and familiarize themselves with the CCCS WLSM guidelines in advance of the workshop. Presentations focused on the development and content of the CCCS WLSM guidelines, implementation and quality assurance tools, coroner perspectives on quality assurance in WLSM and guiding principles for deceased donation following WLSM. Refer to Appendix D*: Workshop Agenda* for details.

Each segment of the workshop was structured around expert presentations and guideline alignment documents designed to stimulate discussion and inform deliberations. The meeting was professionally facilitated. Participants were tasked with reviewing and refining draft statement of principles, implementation and quality assurance tools, and asked to identify strengths, gaps, areas of concern and recommended revisions. Participants were provided with CCCS guidelines to ensure that implementation tools aligned with principles established as best practice in the guidelines. Participant tables reported back in plenary and table and individual worksheets were collected to inform tool revisions. Feedback on the draft guiding principles were incorporated and presented back to participants for validation. After the workshop, participant feedback was collated and summarized by the Planning Committee and used to modify the draft implementation and quality assurance tools. This final report contains recommendations and modified implementation and quality assurance tools stemming from the workshop which were confirmed with participants.

Workshop participants are encouraged to pilot the implementation and quality assurance tools and provide feedback around additional improvements.

The planning committee will develop a comprehensive communication strategy to support knowledge translation and incorporation of the implementation and quality assurance tools into critical care practices. This report and associated tools will be accessible through the Canadian Blood Services' Professional Education website. This report is endorsed by the Canadian Critical Care Society, the Canadian Association of Critical Care Nurses, the Canadian Society of Palliative Care Physicians and will be disseminated to their membership. The output of this workshop will be directed to publication and presentation in appropriate peer venues and journals.

Communication and knowledge translation strategies will incorporate implementation considerations and research opportunities and will engage key stakeholder groups including Accreditation Canada, the Canadian Donation Physician Network, the Organ Donation and Transplantation Expert Advisory Committee, the Donation and Transplant Administrators Advisory Committee and the Deceased Donation Advisory Committee.

Quality assurance in WLSM and donation

The requirement for donation quality assurance processes has been identified in preceding reports including the cDCDD National Guidelines[7] and the Donation Physician Ethics Guide[8], endorsed by the Canadian Medical Association.

As detailed in Figure 3 there are three components of a quality management system. The first component focuses on how services are delivered through documentation of service requirements in policies, protocols, standard operating procedures and implementation tools. The second component focuses on the assessment of how well a service is provided in relation to the expected service requirements. Assessment may include surveys (most importantly, including families), interviews, audits and data analysis. The final component is focused on how services are improved; specifically, the processes of accountability and process improvement which need to be in place to respond to quality incidents or areas of improvement documented in the assessment of service. While this initiative has a focus on guideline implementation, the principles of quality improvement should guide the ongoing process of change to ensure optimal patient and family care.

Figure 3: Quality management system

Note: This figure was prepared May 23, 2016 in preparation for the workshop.

Implementation of CCCS WLSM guidelines

Improving quality of practice in critical care involves the need to effect change. Traditionally, implementation of change often involves a lengthy process of pulling together a team of stakeholders, who review relevant literature and published guidelines and develop some or all of policy, local guidelines, pre-printed orders and other tools. These components are then shared with stakeholders for input. Suggestions are then reviewed and incorporated by the team, after which the products are made available to frontline users. In certain situations, this approach to implementation may be very successful, but at other times uptake by frontline users is minimal and response may be apathetic or even hostile. This approach is also costly in terms of time in development, usually lasting several months to a year, and many person hours spent.

An alternate approach is to "test" change in an iterative manner to ensure the final investment in implementation will affect the change desired. Specifically, we suggest that the tools developed and refined at this workshop be considered templates for hospitals to work from. The first step would be to have the local patient safety team, which may be a stand-alone group or unit program team, review the tools. It is strongly suggested that local patient safety teams have patient representation. If no team exists then one should be assembled. Using a stepwise approach, such as the well-established Plan-Do-Study-Act (PDSA) cycle, review the tools and determine whether changes are required prior to testing it iteratively.

Alternatively, select a tool and test it on one or two patients. Meet and discuss its performance and potential changes required. Test it again and modify further as needed. Try to ensure exposure of the tool to multiple users to get their input. In the end, be confident a large enough cross section of the unit has had an opportunity to assess the tool prior to taking the step of formal implementation. Move on to consider other tools and proceed in the same fashion. This process is much more interactive and allows frontline users an opportunity to provide ongoing input and partner with the patient safety team in implementing change. This approach should lead to a more successful implementation of change.

Challenges to implementation are many. Effecting change takes time and work. Identify a leader who is responsible for the desired change and a team to be engaged in the work. Metrics must be available to measure whether change has been achieved. A balance needs to be struck between desired metrics and workload restraints. Each site should review all tools to determine changes needed for local acceptance. Audits need to be carefully reviewed to ensure that every variable collected is easily measurable within the local workload constraints of those responsible for conducting and analyzing the results. Further, each variable needs to be associated with modifiable factors that allow potential for change. Variables that do not meet these criteria locally should not be retained.

It is mutually beneficial to share your experience with others and to learn from their experiences. Quality improvement is most effective when large groups work and learn together. Ideally, a forum to provide feedback from our workshop should be developed. At a minimum, working and sharing with partner units in your hospital and/or in your region is recommended.

Statement of guiding principles in the application of CCCS guidelines for WLSM in cDCDD

Dr. Shemie presented draft guiding principles for the application of the CCCS WLSM guidelines for participant's reflections and discussion. After plenary discussions and feedback, participants agreed to the following statement of principles.

Guiding Principles

The principles of expert inter-professional critical care must foster a seamless transition into end-of-life care. It is imperative that end-of-life care in the critically ill be of the highest quality, in all circumstances, including that of organ and tissue donation.

High quality end-of-life care:

- maintains dignity, respect and compassion;
- explores the wishes and voices of the patient and family/SDM;
- respects cultural, spiritual values and observances;
- continues to support and partner with patients, families/SDM and health care team members throughout the death experience;
- is consistent with guidelines for WLSM;
- focuses on alleviating pain, distress and providing comfort;
- adheres to the existing medicolegal framework that includes respect for the dead donor rule and precludes intentional hastening of death (notwithstanding medical assistance in dying legislation);
- avoids unnecessary prolongation of the dying process; and
- preserves the opportunity to donate organs and tissues.

These principles of person-centered care in the intensive care unit must be maintained throughout conversations, assessments, and procedures involved in organ and tissue donation. While it is acknowledged that individual WLSM plans may be subject to variability in response to patient/family/SDM priorities, these principles of high quality care must be maintained.

We are collaborating nationally to ensure consistency in application of guiding principles, methods of assessment, patient and family support, and program evaluation at all sites involved in organ and tissue donation within Canada.

CCCS WLSM guideline implementation and quality assurance tools

Implementation and quality assurance tools, which can be customized to specific needs, will support critical care programs in translating the CCCS WLSM guidelines into clinical practice at the bedside. Figure 4 details the 6 implementation and quality assurance tools developed at this workshop.

Figure 4: Definitions of implementation and quality assurance tools

Order Set	A standardized order set created to translate clinical practice guidelines to orders for physicians to initiate, and the team to follow preceding and at the time of the withdrawal of life support.
Checklist	Prior to withdrawal of life support, there are many tasks to be accomplished by a variety of people. The checklist seeks to be a useful clinical tool used by the team of health care providers in organizing the tasks necessary to prepare for, and deliver, the withdrawal of life support.
Documentation Tool	The actions of withdrawal of life support (e.g. extubation, discontinuation of pressors) and the rationale for drug administration as tied to patient symptoms is documented in real time.
Family Information Booklet	This resource will be designed for families of patients who are undergoing withdrawal of support in the ICU and in whom donation after death by circulatory criteria is being considered.
System Audit Tool	This resource is a list of recommended requirements at a hospital level that would be put into place, in advance of cases of withdrawal of life support, to support professionals and families in the process, as determined by the guidelines.
Case Audit Tool	This tool, used on a case by case basis, evaluates adherence to components of the WLSM guideline recommendations. Cumulative analysis of a series of cases of WLSM may identify opportunities for process improvement with the system (hospital).

During distinct sections of the workshop, members of the planning committee provided an overview for each implementation and quality assurance tool. Participants were provided with the draft tools, a discussion guide, discussion worksheet and asked to identify strengths, gaps and revisions specifically focusing on how the tool could be improved. Each table identified a member to record table discussions and recommendations and to report back to plenary. Each table's discussion notes were collected and collated. Plenary discussions and table notes informed revisions to the draft documents. The tools were designed to be used as is, or customized for a program's specific needs. Access to editable formats is provided for customization.

The final tools are presented below and editable templates are provided as attachments in this PDF:

- order set template
- checklist template
- documentation tool template
- family information tool template
- system audit template
- case audit template
- WLSM policy template

Standardized WLSM order set

Preparing for withdrawal of life-sustaining measures (WLSM)

☒ Notify organ donation organization (ODO) of plan to WLSM

☒ Arrange private space for patient and family members, if available

☒ Liberalize visitation

☒ Consult Spiritual Care/Social Work (if desired by patient or substitute decision maker)

☒ Discontinue all previous enteral feeds, medications (except vasoactive and those for pain and symptom management), maintenance IV fluids, blood work, dialysis, and radiographs

☒ Discontinue routine vital sign monitoring

☒ Discontinue neuromuscular blockade (if neuromuscular blocking agents have been used in the past 4 hours, assess train-of-four. If train-of-four is <4/4, consider delaying WLSM or use a modified ventilator weaning)

☒ Confirm do not resuscitate orders are documented

Pharmaceutical management of distress

Pain and dyspnea

☐ **MOR**phine 100 mg in 100 mL 0.9% NaCl infusion at_____mg/h

- ☐ For pain or dyspnea, give additional **MOR**phine IV bolus of_____mg q15 minutes PRN (suggest: 2 mg if opioid-naïve or 2x the hourly infusion rate if already receiving a morphine infusion)
- ☐ If patient receives more than 2 boluses in one hour, THEN start an infusion at 2 mg/h or double the current infusion rate. Adjust the bolus dose to 2x the hourly rate.
- ☐ If the pain or dyspnea persists, notify MD

☐ fenta**NYL** 1,000 mcg in 100 mL 0.9% NaCl infusion at_____mcg/h

- ☐ For pain or dyspnea, give additional fenta**NYL** IV bolus of_____mcg q5 minutes PRN (suggest: 25 mcg if opioid-naïve or 1x the hourly infusion rate if already receiving a fentanyl infusion)
- ☐ If patient receives more than 2 boluses in one hour, THEN start an infusion at 50 mcg/h or double the current infusion rate. Adjust the bolus dose to 1x the hourly rate.
- ☐ If the pain of dyspnea persists, notify MD

☒ Document on WLSM Documentation Tool (heart rate, respiratory rate and signs and/or symptoms of pain or dyspnea when providing a bolus or adjusting the infusion rate)

Anxiety and agitation

☒ Optimize analgesia prior to adjusting sedation

☐ Midazolam 100 mg in 100 mL 0.9% NaCl infusion at_____mg/h

(use current dose if patient is already receiving midazolam, but patient may not require sedation)

- ☐ For signs of anxiety or distress, give additional midazolam IV bolus equal to the hourly dose (suggest: 2 mg for patients not receiving an infusion) given q5 minutes PRN
- ☐ If the patient receives more than 2 boluses in one hour, THEN start an infusion at 2 mg/h or double the current infusion rate
- ☐ If the anxiety or agitation persists, notify MD

☐ Propofol 10 mg/mL premixed vial, infusion at_____mg/kg/h

(use current dose if patient is already receiving propofol, but patient may not require sedation)

- ☐ For signs of anxiety or distress, give additional propofol IV bolus (suggest: 10-20 mg for patients not receiving an infusion) given q5 minutes PRN
- ☐ If the patient receives more than 2 boluses in one hour, THEN start an infusion at 0.5 mg/kg/h or double the current infusion rate
- ☐ If the anxiety or agitation persists, notify MD

☒ Document Richmond Agitation-Sedation Scale (RASS) score and assess for signs and/or symptoms of anxiety pre and post each bolus dose or rate adjustment

Additional medications

☐ Metoclopramide 10 mg IV q6h PRN for nausea

☐ Glycopyrrolate 0.4 mg IV q4h PRN for oral secretions

Withdrawal of physiologic support

When the family is ready for withdrawal of life support:

☒ Deactivate defibrillator and discontinue transvenous or transcutaneous cardiac pacing

☒ Deactivate mechanical hemodynamic support, aortic balloon pump, ventricular assist device, ECMO

☒ Discontinue all vasoactive medications

When the patient is unresponsive to verbal stimuli (RASS -4 or -5) and signs of respiratory distress (accessory muscle use, tachypnea, nasal flaring) are managed:

☒ Discontinue respiratory support

For patients mechanically ventilated:

☐ RRT to discontinue mechanical ventilation. Choose one of the following options:

- ☐ Rapidly wean ventilator to FiO2 0.21l, PEEP 5cm H20, PS 5cm H20. If patient is comfortable on minimal settings for 5 minutes, extubate to room air.
- ☐ Extubate to room air
- ☐ Other: _____

For patients on non-invasive ventilation or oxygen therapy:

☐ RRT to discontinue non-invasive ventilation or oxygen therapy and place on room air

WLSM checklist

Review checklist with team early, in advance of initiating withdrawal of life-sustaining measures (WLSM).

Decision making and documentation

	Action	Notes
☐	The patient's capacity to make decisions and legally correct substitute decision maker has been recorded.	
☐	A multidisciplinary team meeting has occurred and the outcome has been documented in the medical record. Any consulting services with a pre-existing or close relationship (e.g. surgical services, oncology) were involved in the meeting or the decision.	
☐	The plan of care has been documented in the chart and the patient, where possible, and family is aware of this plan.	
☐	An order to WLSM and an order not to provide cardiopulmonary resuscitation upon death is recorded in the chart.	
☐	A description of WLSM has been provided to the family and translation offered, where required.	

Preparing for WLSM

	Action	Notes
☐	Liberalized family visiting has been offered and, where possible, a space for the family to gather privately has been arranged. The family has been offered an opportunity to participate in patient care during WLSM.	
☐	The organ donation organization (ODO) has been notified of the patient's imminent death.	*Notification* to ODO prior to a planned withdrawal of life support conversation. *Referral* to ODO for collaborative planned approach should occur after the decision to WLSM.
☐	Ensure patient and/or family have been offered the opportunity to donate organs and tissues according to regional best practice.	The inter-professional team members will jointly develop a plan for approaching and discussing donation options.

Consultative supports

	Action	Notes
☐	Spiritual care, religious and culture supports are offered, including involvement of the patient's own clergy.	
☐	The opportunity for social/religious/cultural observances has been offered, including an attempt to accommodate any last wishes of the patient.	
☐	A social work consultation has been considered and offered, where appropriate.	
☐	Respiratory therapist is aware of WLSM plans.	
☐	Palliative care consultation is considered and offered, where appropriate.	
☐	***For cDCDD cases:*** Where indicated, the Coroner or Medical Examiner service has been contacted, role explained to the family and appropriate authorization for donation obtained prior to WLSM.	

Family and team review

	Action	Notes
☐	WLSM order set completed by physician and placed on the chart. An approach for modification of these orders following WLSM is reviewed with the nurse, physician and respiratory therapist to ensure clear approach when the ordered medications fail to obtain goals.	
☐	The specific goals of symptom management are reviewed.	
☐	Approach to symptom management reviewed with health care team, including: • possible symptoms which may occur after WLSM • medications used to treat possible symptoms • medication used to treat any anticipated symptoms not yet present	
☐	Orders reviewed. ICU nurse, respiratory therapist and other team members who will be present during WLSM are comfortable with treatment plan.	
☐	Orders written for discontinuation of all non-comfort medications, blood transfusions, dialysis, vasopressors/inotropes, nutrition, antibiotics, intravenous fluids and laboratory work.	
☐	Orders written for pace and sequence of WLSM, including mechanical ventilation and artificial airway.	

☐	The offer is made to have family present for WLSM and end-of-life care.	
☐	The room preparation and location of WLSM is reviewed and planned, including removing as much equipment and technology as possible from the room. Ambiance room setup preferences are considered.	
☐	Approach to monitoring has been reviewed with the family and health care team. Monitoring flowsheet at bedside.	
☐	Team huddle occurs prior to withdrawal of life support and this includes the family, ensuring everyone understands their roles and actions that will occur prior to and following death.	
☐	Post an unobtrusive signal to other ICU team members that WLSM is occurring.	

During withdrawal of life support

	Action	Notes
☐	Symptom management is provided according to the order set and documented on the WLSM documentation tool.	

Donation after circulatory determination of death ONLY

	Action	Notes
☐	The necessity of monitoring for cDCDD death declaration is reviewed with the family.	
☐	Procedure for death declaration (an organ and/or tissue donation, where required) has been reviewed.	
☐	The possible outcomes, including not dying in a manner which allows organ donation are reviewed.	Patients and families are reminded the gift of life is given in the decision to donate.
☐	The administration of heparin for cDCDD, where applicable, has been reviewed, including consent, and a dose has been ordered in consultation with the organ donation organization (ODO).	

Registered Nurse:

Name	Signature	Date YYYY / MM / DD

Physician

Name	Signature	Date YYYY / MM / DD

WLSM documentation tool template

DATE INITIATED YYYY / MM / DD	TIME INITIATED :	FOLIO____of ___	PATIENT IDENTIFICATION

Withdrawal of life-sustaining measures symptom based critical care

Instructions for Use

1. This is a template for a nursing documentation tool to chart events, vitals, and medication administration from the time of withdrawal of life-sustaining measures (life support) and death, transfer to a unit outside the ICU or when 12 hours has lapsed. This template may be used, or it may inform the development of a similar organizational tool for your local unit. Units may want to consider the use of additional RT and or MD documentation tools.
2. Once this document is invoked, a notation in the usual ICU charting document (flowsheet or electronic charting) should be made to indicate that WLSM flowsheet charting has been initiated – e.g. "See WLSM flowchart".
3. If a patient remains alive for an extended period of time following WLSM, usual charting is resumed and a notation should be made in both this flowchart and the usual chart to indicate the transition – e.g. "WLSM flowsheet ended".
4. The minimum charting requirements are as follows:
   a. vital signs are charted just prior to withdrawal and then hourly for the next 12 hours;
   b. rationale for any bolus medication or change in infusion rate is included;
   c. action plans (as detailed in the orders) should be copied on to page 2 of this document prior to withdrawal; and
   d. time of death, declaring providers, and method of declaration must be charted on page 3.
5. If a symptom (listed A-K) is used to justify a bolus or infusion rate change, the letter corresponding to the symptom should be circled.
6. If additional narrative charting is necessary and does not fit on the flow chart, a number can be written and circled to indicate the reader should review the continuation of the note on page 3 of this document.
7. Symptom documentation supports ease of use and compliance. However, the use of validated scales such as BPS, CPOT and RDOS would provide additional value and more objective data. Programs should consider the use of validated scales.
8. Samples of pain, sedation and respiratory scales have been attached as an appendix on page 4.

Pre-WLSM Huddle

Date initiated	YYYY / MM / DD
Time	:
Attending	☐ MD ☐ RN ☐ RT ☐ Spiritual care

Item	Stopped at		Initials
	Date	Time	
Vasoactive agents / pressors	YYYY / MM / DD		
Extubation	YYYY / MM / DD		
Other	YYYY / MM / DD		

WLSM Initiated

Date	YYYY / MM / DD
Time	:

PATIENT IDENTIFICATION

Time	Provider Initials	Vitals			Pain, Dyspnea and Discomfort Management Narcotic: _____ ***Note:*** *The Behavioral Pain Scale (BPS) and the Critical-Care Plan Observation Tool (CPOT) are valid and reliable and could be substituted*				Agitation and Anxiety Benzodiazepine / Anxiolytic				Response to changes in drug administration, sedation/pain meds and other comments
		HR	RR	BP	Respiratory Distress & Air Hunger A. Fearful facial expression B. Accessory muscle use C. Paradoxical breathing D. Nasal flaring E. Family concern	Pain and Discomfort F. Diaphoresis G. Rigidity H. Wincing I. Shutting of eyes J. Clenched fists K. Verbalizing / Moaning	Infusion Rate	Bolus Dose	RASS or SAS	Other	Infusion Rate	Bolus Dose	
					A B C D E F G H I J K								
					A B C D E F G H I J K								
					A B C D E F G H I J K								
					A B C D E F G H I J K								
					A B C D E F G H I J K								
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					A B C D E F G H I J K								
					A B C D E F G H I J K								
					A B C D E F G H I J K								
					A B C D E F G H I J K								

☐ Continued in Folio

DATE OF DEATH	TIME OF DEATH
YYYY / MM / DD	:
DEATH WAS PRONOUNCED BY: PHYSICIAN 1	PHYSICIAN 2
OTHER NOTES	

PATIENT IDENTIFICATION

***** The below table refers to numbered charting notes from page 2 of this document. *****

#	Note	#	Note
1		13	
2		14	
3		15	
4		16	
5		17	
6		18	
7		19	
8		20	
9		21	
10		22	
11		23	
12		24	

Post-WLSM huddle

Date initiated	YYYY / MM / DD
Time	:
Attending	☐ MD ☐ RN ☐ RT ☐ Social work ☐ Spiritual care ☐ Other

Charting healthcare practitioners

Initials	Name	Designation

Examples of pain and sedation scales

Richmond Agitation-Sedation Scale (RASS)

Scale	Label	Description	
+4	COMBATIVE	Combative, violent, immediate danger to staff	VOICE
+3	VERY AGITATED	Pulls to remove tubes or catheters; aggressive	
+2	AGITATED	Frequent non-purposeful movement, fights ventilator	
+1	RESTLESS	Anxious, apprehensive, movements not aggressive	
0	ALERT & CALM	Spontaneously pays attention to caregiver	
-1	DROWSY	Not fully alert, but has sustained awakening to voice (eye opening & contact >10 sec)	
-2	LIGHT SEDATION	Briefly awakens to voice (eyes open & contact <10sec)	
-3	MODERATE SEDATION	Movement or eye opening to voice (no eye contact)	
	If RASS is ≥ -3 proceed to CAM-ICU (is patient CAM-ICU positive or negative?)		
-4	DEEP SEDATION	No response to voice, but movement or eye opening to physical stimulation	TOUCH
-5	UNAROUSABLE	No response to voice or physical stimulation	
	If RASS is -4 or -5 → STOP (patient unconscious), RECHECK later		

Sessler, et al. Am J Respir Crit Care Med 2002. 166: 1338-1344 Ely et al. JAMA 2003.286. 2983-2991

Riker Sedation-Agitation Scale (SAS)

Score	Term	Descriptor
7	Dangerous Agitation	Pulling at ET tube, trying to remove catheters, climbing over bedrail, striking at staff, thrashing side-to-side
6	Very Agitated	Requiring restraint and frequent verbal reminding of limbs, biting ETT
5	Agitated	Anxious or physically agitated, calms to verbal instructions
4	Calm and Cooperative	Calm, easily arousable, follow commands
3	Sedated	Difficult to arouse but awakens to verbal stimuli or gentle shaking, follows simple commands but drifts off again
2	Very Sedated	Arouses to physical stimuli but does not communicate or follow commands, may move spontaneously
1	Unarousable	Minimal or no response to noxious stimuli, does not communicate or follow commands

Behavioral Pain Scale (BPS)

Item	Description	Score
Facial expression	Relaxed	1
	Partially tightened (e.g. brow lowering)	2
	Fully tightened (e.g. eyelid closing)	3
	Grimacing	4
Upper limb movement	No movement	1
	Partially bent	2
	Fully bent with finger flexion	3
	Permanently retracted	4
Compliance with mechanical ventilation	Tolerating movement	1
	Coughing but tolerating ventilation for the most of time	2
	Fighting ventilator	3
	Unable to control ventilation	4

*Note: BPS score ranges from 3 (no pain) to 12 (maximum pain).

Respiratory Distress Observation Scale (RDOS)

Variable	0 pts	1 pt	2 pts
Heart rate per minute	< 90	90 – 109	> 109
Respiratory rate per minute	< 19	19 – 30	> 30
Restlessness: non-purposeful movements	None	Occasional, slight	Frequent
Accessory muscle use: rise in clavicle during inspiration	None	Slight	Pronounced
Paradoxical breathing	None	-	Present
Grunting at end-expiration: guttural sound	None	-	Present
Nasal flaring: involuntary movement of nares	None	-	Present
Look of fear	None	-	Eyes wide open, facial muscles tense, brow furrowed, mouth open

Journal of Palliative Medicine. 2010; 13(3): 285-290

Critical-Care Pain Observational Tool (CPOT)

Indicator	Score		Description
Facial expressions	Relaxed, neutral	0	No muscle tension observed
	Tense	1	Presence of frowning, brow lowering, orbit tightening and levator contraction or any other change (e.g. opening eyes or tearing during nociceptive procedures)
	Grimacing	2	All previous facial movements plus eyelid tightly closed (the patient may present with mouth open or biting the endotracheal tube)
Body movements	Absence of movement or normal position	0	Does not move at all (doesn't necessarily mean absence of pain) or normal position (movements not aimed toward the pain site or not made for the purpose of protection)
	Protection	1	Slow, cautious movements, touching or rubbing the pain site, seeking attention through movements
	Restlessness/Agitation	2	Pulling tube, attempting to sit up, moving limbs/thrashing, not following commands, striking at staff, trying to climb out of bed
Compliance with the ventilator (intubated patients) OR Vocalization (extubated patients)	Tolerating ventilator or movement	0	Alarms not activated, easy ventilation
	Coughing but tolerating	1	Coughing, alarms may be activated but stop spontaneously
	Fighting ventilator	2	Asynchrony: blocking ventilation, alarms frequently activated
	Talking in normal tone or no sound	0	Talking in normal tone or no sound
	Sighing, moaning	1	Sighing, moaning
	Crying out, sobbing	2	Crying out, sobbing
Muscle tension Evaluation by passive flexion and extension of upper limbs when patient is at rest or evaluation when patient is being turned	Relaxed	0	No resistance to passive movements
	Tense, rigid	1	Resistance to passive movements
	Very tense or rigid	2	Strong to passive movements or incapacity to complete them
Total		/ 8	

*Note: When a patient's CPOT is >3, the team will evaluate pain sources and modify/enhance pain management. CPOT sensitivity = 86% and specificity = 78% (Gélinas C, J Pain Sympt Man 2009).

Adapted from Gélinas et al., AJCC 2006; 15(4):420-427). Reproduced with permission. For more information about the CPOT use, contact the author at celine.gelinas@mcgill.ca

WLSM family information

What does it mean to withdraw life-sustaining measures or life support?

Your care team is there to help you and your loved one. However, when a patient is very ill, the care team cannot always help them get better despite their best treatments, efforts and hopes. In these situations, the aim is to keep your loved one comfortable while allowing them to die with dignity and respect.

Withdrawal of life-sustaining measures involves several steps, throughout which respect, dignity and your loved one's comfort is the care team's main priority. When the decision is made to withdraw life support and allow death to occur, you can expect the following to take place:

- Medications that control blood pressure or heart rate will be stopped
- The ventilator (breathing machine) will be turned off and the breathing tube is usually removed
- If your loved one is on dialysis, it will be discontinued
- The vital signs monitor may be turned off; staff will watch your loved one for comfort rather than checking his or her vital signs
- Routine tests like blood work and X-rays will no longer be ordered
- Intravenous fluids will be decreased or stopped
- Tube feeding will be stopped and the feeding tube may be removed
- Any treatments or medications that are not aimed at treating symptoms, increasing comfort, maintaining dignity or supporting cultural-social well-being will also be stopped

Adjustments may occur to meet the needs of your family and your loved one. Your care team will discuss these steps with you in more detail.

What can I expect after life support is withdrawn?

It is difficult to predict when death will occur. In some cases, it comes quickly. In other circumstances, it may occur several hours or even days after life support is withdrawn. Regardless of the amount of time before death, your loved one will continue to receive care.

What symptoms could my loved one experience and how will these be treated?

Your loved one will be closely watched for signs of pain or distress. If you notice any change that concerns you, tell a member of your care team.

Pain and shortness of breath:

- Pain may cause changes in facial expression, agitation, or other signs of discomfort. Pain will be treated with medications like morphine which can be quickly adjusted to ensure comfort.
- Shortness of breath may occur, particularly as the breathing machine is turned off and the breathing tube removed. Medications are given to ensure that your loved one is comfortable.

- When pain and shortness of breath are treated with medication, the dose given will be based on the amount of comfort medication your loved one is already receiving. Studies have shown that giving medication for comfort does not shorten life. There is no reason to over treat or undertreat pain or shortness of breath.

Changes in breathing pattern:

- You may notice pauses in breathing, snoring, or rapid shallow breathing. This is a normal part of the dying process and not necessarily a sign of discomfort. It generally does not need to be treated.
- Changes in swallowing may cause saliva to pool at the back of the mouth and cause a rattling or gurgling noise when your loved one breathes. This is likely not uncomfortable for your loved one. However, medications and treatments may be given if it causes discomfort.

Anxiety and agitation:

- Signs of agitation can include restlessness, frequent movements, or pulling at blankets and tubes. Your loved one will be watched closely for these symptoms and provided sedative medications as needed.

Hunger and thirst:

- At end-of-life, most people do not feel hungry or thirsty. As the body's systems begin to shut down it can become difficult for people to tolerate food and fluids. For this reason, stopping fluids and tube feeding during this time is recommended. Some people experience discomfort from dry lips or a dry tongue. This is best treated with moist swabs or an artificial saliva spray rather than giving fluids intravenously.

How can I support my loved one during this time?

You are welcome to be in the room as life support is stopped. This is a very personal decision. Some families and family members prefer to be present and others do not. Your health care team will support any decision you make. Simply sitting with your loved one, speaking quietly with them, and holding their hand can help to provide comfort.

If you would like to bring in items like photos, music, and letters from friends and family to celebrate the life of your loved one, you may do so. If there are cultural or religious rituals that are important to your loved one, you may bring in your own spiritual leader or ask your care team to help arrange this.

What if I need support?

During this time, you may have many different feelings such as sadness, anger, fear, guilt, or even relief. It can be helpful to talk with the friends and family members about your feelings and fears. All members of your health care team, including the doctors, nurses, respiratory therapists, social workers and spiritual care providers are there to support you during this very difficult time. If you would like some time alone, there are spaces in the hospital for quiet reflection or prayer.

Community resources are available to support your family during and after the end-of-life process. Your care team can provide more information on what support is available.

If I have questions, who can I ask?

If you are concerned about your loved one's comfort at any time or have questions about their symptoms and how they are being treated, please let a member of your care team know. Sometimes it helps to write down questions or concerns.

There are many members of the team caring for your loved one. With around-the-clock care, you may meet doctors, nurses, and respiratory therapists who will become new members of your care team. Feel free to ask questions and introduce yourself. Your care team is there to support you and your family throughout end-of-life care.

What if our loved one wanted to be an organ or tissue donor?

Organ and tissue donation may be an option following death. Experts in organ and tissue donation are available to answer questions and support you and your family through the donation process. Your care team may raise the issue of donation with your family. Please feel free to talk to your team about organ and tissue donation.

If your loved one wishes to donate his or her organs and or tissues, the timing for withdrawal of life support will be discussed. The organ and tissue donation teams and the physicians from the intensive care unit will be a part of the discussion with you and your family. All teams and team members will ensure your loved one is comfortable. The medications they receive for comfort will not change. Additional medications and tests may be required. If so, the organ donation coordinator will discuss this with you.

You will be able to be with your loved one when life support is removed. Vital sign monitors will remain in place. When your loved one dies, two physicians will confirm that death has occurred. Your loved one will then be moved to the operating room for donation. If you wish to be with your loved one after organ donation has taken place that can be arranged.

Even if your loved one wished to be an organ donor, donation may not always be possible. The dying process is unpredictable and may take longer than expected. In some cases, your loved one's organs may not have received enough oxygen to work well for someone else. It is important to remember the gift of life is in the decision to donate. We recognize the potential disappointment when organ donation is not possible and will do all we can to support you through this.

The timeline for tissue donation is different from organ donation and may occur within 24 hours of death.

Staff from the intensive care unit and the organ and tissue donation teams will be available to answer any questions you may have. If you wish to discuss organ donation or your decision to do so, please ask to speak to a member of your care team at any time.

Questions?

You may still have questions about what happens at end-of-life. Sometimes it helps to write down your questions. Please don't hesitate to ask questions and raise any concerns you may have with any member of your care team. Your care team is there to support you, your loved one and your family through this difficult time.

WLSM system audit

DATE YYYY / MM / DD	HOSPITAL NAME	UNIT

The purpose of this audit is to enhance the quality of the process of withdrawal of life-sustaining measures (WLSM) in special care units where life support measures are used. Intensive care units (general or specialized), cardiac care units, high acuity units, step-down units, etc. Please note that this applies to the **clinical** process of WLSM, and NOT the decision-making process.

As a unit, your task is to document whether you have the following best practices in place in advance of WLSM from a patient. A comment section is available for your use. **Please comment on any "No" answers**. These are based on the Canadian Critical Care Society's Guidelines on Withdrawal of Life-Sustaining Measures.

To be completed by Physician and Administration lead for the unit, in consultation with front line staff.

Policy and procedure background work

Policy and Procedure	Yes	No	Comments
Does the organization have a specific policy on WLSM?			
Does the policy reference the CCCS Guidelines on WLSM?			
Does the organization have an organ and tissue donation committee?			
Has the donation committee reviewed the CCCS guidelines for WLSM and local policy, if present?			
Does the organization routinely evaluate or audit cases of WLSM? If yes, is there a case audit tool?			
Is there a process in place to assess and communicate audit results at defined intervals? • someone responsible to conduct audits • person responsible to analyze and provide feedback • person responsible to act on results			
Is there a process to develop an inter-professional care plan for WLSM for each patient? (e.g. mandatory huddle to discuss roles and responsibilities)			
Are there regular education sessions on staff roles in WLSM for:			
• physicians			
• nurses			
• RTs			
Please check yes/no for each and comment on frequency.			
Notes: *(any missing item should be addressed in the action plan below)*			

Preparing for WLSM

Preparing for WLSM	Yes	No	Comments
Can the unit provide a private room for patients at end-of-life? *If yes, please comment on frequency (e.g. always, usually, sometimes).*			
Is there a separate family room for family to gather, particularly if their loved one is at end-of-life? *If yes, please comment on frequency (e.g. always, usually, sometimes).*			
Are there environmental aids (e.g. signs) identifying, in an unobtrusive way, the process of WLSM has started (facilitates liberal visiting, etc.)?			
Is acute grief support available for families? *If so, please specify who provides this.*			
Are families welcome to be present for WLSM and participate in the patient care before, during and after?			
For challenging or complicated cases, practitioners are encouraged to seek advice and support from colleagues.			
Notes: *(any missing item should be addressed in the action plan below)*			

Assessment of distress during WLSM

Assessment of distress during WLSM	Yes	No	Comments
Is there a specific documentation tool for documenting symptoms and treatment of symptoms in WLSM?			
Are standardized scoring systems or some objective measure of assessment embedded in this documentation for:			
• pain			
• respiratory distress			
• agitation			
• delirium			
Please check yes/no for each.			
Is there education for staff to ensure families can also contribute to the assessment of symptoms at end-of-life?			
Notes: *(any missing item should be addressed in the action plan below)*			

Discontinuation of treatment and monitoring

Does the unit have the following materials available?	Yes	No	Comments
Guideline and/or clinical protocol for WLSM process (step-by-step procedure)			
Checklist to support the WLSM process in real time with each patient			
Pre-printed standardized orders for WLSM			
Educational material for staff for WLSM process			
Educational material for family for WLSM process			
Documentation tools for WLSM process			
Notes: *(any missing item should be addressed in the action plan below)*			

Following WLSM and patient death

Are the following in place?	Yes	No	Comments
Bereavement material available for family			
Family satisfaction with WLSM survey. *If yes,* • *how frequently is it done?* • *who sends out surveys?* • *who analyzes results of surveys?*			
Process for staff debriefing after WLSM *If yes,* • *is it formalized?* • *who decides on need for debrief?* • *who conducts debrief?*			
Notes: *(any missing item should be addressed in the action plan below)*			

System audit follow up action items and accountability

ACTION ITEM	ACCOUNTABILITY

PERFORMED BY	DATE YYYY / MM / DD	TIME :

System audit tool helped facilitate discussion: ☐ Yes ☐ No

Tool requires revision: ☐ No ☐ Yes – Feedback provided to_____

A repeat system audit will be completed for this unit in_____months (suggest: 12)

WLSM case audit

DATE WLSM STARTED YYYY / MM / DD	IDENTIFIER 1	IDENTIFIER 2
NAME	MRN	☐ DCD ☐ No donation

Cause of Death/Decision for WLSM: _____

Event timing

Event	Time	Comments
Withdrawal of vasopressors	Start : Complete :	
Withdrawal of mechanical ventilation	Start : Complete :	
Withdrawal of supplemental oxygen	Start : Complete :	
Extubation	:	
Death	Date / Time YYYY/MM/DD :	
Transfer from unit prior to death. *If yes, document date and time.*	☐ No ☐ Yes Date / Time YYYY/MM/DD :	
Bedside monitors	☐ ON ☐ OFF	
Notes: *(any missing item should be addressed in the action plan below)*		

Preparation for WLSM

Location of documentation sought in the audit predefined by site. Do not include items suggested below if not routinely documented at your site. Location can be in nursing or physician's notes or use of specific checklist completed for WLSM. A checklist is strongly recommended where items match the audit.

Which of the following are clearly *documented*?	**Yes**	**No**	**Comments**
Multidisciplinary care plan for WLSM			
Notification of Organ Donation Organization			
Patient/family offered the opportunity for organ and tissue donation			
Pre-WLSM huddle of physician, RN, RT, social work, others			
Explicit decision made regarding use of bedside monitors and in consultation with family			
Signal/sign posted that WLSM is occurring			
Spiritual/culture needs of patient and family discussed prior to WLSM			
Spiritual/culture support offered to patient and family			
Family encouraged and permitted to participate in patient care before, during and after WLSM			
Notes: *(any missing item should be addressed in the action plan below)*			

Process of WLSM

Steps	**Yes**	**No**	**Comments**
Family present during WLSM			
Concern noted regarding RN availability during WLSM			
Concern noted regarding RT availability during WLSM			
Concern noted regarding MD availability during WLSM			
Standardized order set available and signed in advance of WLSM *Check documented times.*			
Notes: *(any missing item should be addressed in the action plan below)*			

Assessment of distress and symptom relief during WLSM

It is assumed each unit will use only one scoring system for symptoms.

Is the following documented in the RN notes?	Consistently	Inconsistently	Not at All	Comments
Pain score used				
Sedation score used				
Respiratory distress score used				
Delirium score used				
Medication name(s) and dose(s) used to treat anticipated symptoms with documented rationale				
For evident symptoms, administration of medication included documentation of:	**Consistently**	**Inconsistently**	**Not at All**	**Comments**
• score prompting use of medications				
• dose				
• response				
Notes: *(any missing item should be addressed in the action plan below)*				

Following death

The following items are suggestions. Documentation must be clear and a post WLSM checklist matching the items below is suggested.

Follow up	Yes	No	Comments
Grief literation/information/support offered to family			
Referral to community bereavement support			
Suggestion whether to review case documented			
Notes: *(any missing item should be addressed in the action plan below)*			

Case audit follow up action items and accountability

ACTION ITEM	ACCOUNTABILITY

PERFORMED BY	DATE YYYY / MM / DD	TIME :

Case audit tool helped facilitate discussion: ☐ Yes ☐ No

Tool requires revision: ☐ No ☐ Yes – Feedback provided to_____

WLSM policy

Withdrawal of life-sustaining measures (WLSM)

The inter-professional team's primary responsibility is to ensure that decisions are being made in the best interests of the patient which should be guided by the following principles:

- to honor the patient's wishes at end-of-life;
- to offer care that is collaborative with a shared-decision making model;
- to support family/substitute decision maker (SDM) during the difficult decision-making process;
- to align evidence-based interventions with the patient and family's values, beliefs and goals;
- to alleviate suffering and prevent harm; and
- to communicate clearly and respectfully with the patient, family and inter-professional team.

Prior to WLSM, an inter-professional care plan should be created for each patient focusing on symptom management, order and pace of withdrawal, and family support. Referral to an organ and tissue donation program, if appropriate, should also be initiated.

WLSM should be carried out in accordance with the 2016 Canadian Critical Care Society's Guidelines, and applied in accordance with the following principles, while respecting the needs and wishes of patients and their families.

The principles of expert inter-professional critical care must foster a seamless transition into end-of-life care. It is imperative that end-of-life care in the critically ill be of the highest quality, in all circumstances, including that of organ and tissue donation.

High quality end-of-life care:

- maintains dignity, respect and compassion;
- explores the wishes and voices of the patient and family/SDM;
- respects cultural, spiritual values and observances;
- continues to support and partner with patients, families/SDM and health care team members throughout the death experience;
- is consistent with guidelines for WLSM;
- focuses on alleviating pain, distress and providing comfort;
- adheres to the existing medicolegal framework that includes respect for the dead donor rule and precludes intentional hastening of death (notwithstanding medical assistance in dying legislation);
- avoids unnecessary prolongation of the dying process; and
- preserves the opportunity to donate organs and tissues.

These principles of person-centered care in the intensive care unit must be maintained throughout conversations, assessments, and procedures involved in organ and tissue donation.

While it is acknowledged that individual WLSM plans may be subject to variability in response to patient/family/SDM priorities, these principles of high quality care must be maintained.

Symptom management

1.1 Objective signs of pain, shortness of breath, agitation, and delirium should be used to guide symptomatic treatment. Neuromuscular blocking agents should be discontinued before withdrawal of life support to aid in symptom assessment.

1.2 Medications should be used both to treat current symptoms and in anticipation of symptoms that are likely to arise. The rationale for giving any comfort medication should be documented.

1.3 A specific titration schedule for opioid and sedative medications should be utilized and medications should be titrated to symptoms with no dose limit.

1.4 Pain and dyspnea should be treated with opioids before employing the use of sedatives for anxiety or agitation.

1.5 Medications to alleviate other symptoms such as excessive secretions, post-extubation stridor, and nausea should also be included in the care plan.

Discontinuation of treatment

2.1 Liberalized family visiting should be offered and where possible, a space for the family to gather privately should be arranged. The approach to monitoring should be reviewed with the family/SDM and the health care team. An unobtrusive signal should be displayed outside to alert members of the health care team that WLSM is occurring.

2.2 The pace and order of withdrawal should be individualized to the needs of the patient. However, consideration should be given to withdrawing vasopressors and inotropes first, followed by mechanical ventilation and the artificial airway.

2.3 All non-comfort focused medications and interventions should be discontinued including dialysis, transfusions, parenteral feeding, enteral tube feeding, intravenous fluids, blood work, and imaging studies.

2.4 Providing that the patient is comfortable, mechanical ventilation should be withdrawn as quickly as possible. In the absence of contraindications, the patient should be extubated to room air and non-invasive ventilation or supplemental oxygen should not be provided except for comfort.

2.5 Implantable cardiac defibrillators should be deactivated prior to WLSM, and consideration should be given to discontinuing or disabling transvenous or permanent pacemakers.

Family/substitute decision maker support

3.1 Family/SDM should be involved in shared-decision making.

3.2 Family/SDM should be invited to be present at the time of withdrawal and assist in patient care. This can include helping to provide comfort to the patient and assisting in symptom assessments.

3.3 Family/SDM should be offered spiritual and bereavement supports and efforts should be made to accommodate any religious or cultural rituals, including involvement of their own religious leaders.

3.4 Following the death of their loved one, family members should receive information on community bereavement resources along with a letter of condolence.

3.5 To facilitate excellent bereavement support, inter-professional team members should receive education on the grieving process and how to provide acute support.

3.6 Physicians should be available as needed for family/SDM and staff once life support has been withdrawn to answer questions and offer additional support.

Case audit and review

4.1 Debriefing with the inter-professional team should be considered after each WLSM case.

4.2 Case audits should be performed after each case to ensure that protocols were followed and to identify opportunities for improvement.

Donation after circulatory determination of death (cDCDD)

5.1 Patients should be referred to the provincial organ and tissue donation agency when there is a plan in place to WLSM.

5.2 The decision to proceed with WLSM should not be influenced by any member of the organ or tissue donation team. The patient and/or family/SDM should not be approached to discuss donation until after the decision to WLSM has been made by the patient or SDM and the treating team.

5.3 The principles of care during WLSM should be the same regardless of whether or not the patient is a candidate for organ donation, although the treatment plan may differ slightly in terms of symptom management and comfort medications. The orders for WLSM should be written by a member of the ICU team without input from the organ donation team.

5.4 Explicit consent should be obtained for the administration of any medications that are being prescribed to optimize the chances of organ donation, but are not normally part of WLSM, such as unfractionated heparin.

5.5 If the dying process is prolonged and the patient is no longer a candidate for organ donation, symptomatic management and family/SDM support will proceed as per the protocol outlined above. Tissue donation may still be appropriate and feasible in these situations.

For further details regarding organ and tissue donation after death by circulatory criteria, please consult your institutional organ and tissue donation policy.

Research opportunities

Throughout the workshop participants identified research opportunities in relation to WLSM and deceased donation. The key areas for future research identified included:

- Support
  - WLSM decision support for families and for health care professionals
  - how to involve families in WLSM
  - support practices in low resource settings
- Debriefing
  - pre and post WLSM, best practices; who, when and how
- Bereavement
  - best practices
  - how to best support families within the ICU and longer-term post death
  - preparing health care professionals and care providers in provision of immediate and future support
- Perspectives
  - the provision and impact of spiritual, religious and cultural care
- WLSM Practices & Education

Health care providers expressed concerns regarding the perception of hastening death within the context of WLSM and donation whereas family member participants concerns focused more around the prolongation of death. A future research topic for consideration may be to better understand whether health care provider's assumptions about family's concerns align with what families are experiencing.

Additional areas for research in relation to WLSM and donation were identified including:

1. Are decisions to WLSM influenced by the potential to donate organs and/or tissues?
2. How have recently developed guidelines for WLSM influenced/impacted practice in Canadian intensive care units?
3. How can bereavement support be implemented into low resource critical care settings?
4. Are decision support/decision aids useful in facilitating discussions regarding goals of care as well as organ and tissue donation?
5. What are best-practices related to spiritual/religious/cultural care within the context of organ and/or tissue donation?
6. What are the experiences of family members regarding: i) family presence during WLSM; ii) debriefing following WLSM; iii) bereavement support post WLSM and organ and/or tissue donation?
7. What are the experiences of family members who i) stay at the bedside throughout the process of WLSM; ii) choose not to be present at the bedside throughout the process of WLSM?

8. What are experiences of ICU clinicians and family members regarding the use of continued monitoring during the WLSM?
9. What are the experiences of families who consent to donation after cardio-circulatory death but the patient does not expire within recommended guideline timeframes?
10. Has the prevalence of "consented, not recovered" of "all potential donors" remained consistent over time?
11. What factors constitute "non-recovery" and have these factors stayed consistent over time?
12. Are there instances whereby hastening death related to donation after cardio-circulatory death is ever permissible?
13. What are current trends/practices with respect to consent for a treatment plan in comparison with consent for individual components of a treatment plan?

Communication and collaboration are of high importance in relation to WLSM and donation research; both to be aware of research the community is undertaking and working collaboratively to build on that research and to ensure its dissemination.

Coroner's perspectives on death investigation and cDCDD

Dr. Huyer Chief Coroner, Ontario, Ministry of Community Safety and Correctional Services provided an overview on death investigation. Death investigation is a provincial and territorial responsibility and there is variance in practice between jurisdictions. Four provinces have implemented a Medical Examiner model; the remaining use Coroner models. Medical Examiner models are led by a forensic pathologist who manages the death investigation system which may have non-physician investigators. In the coroner system there is no requirement for physician leadership. Coroners may be nurses, physicians, lawyers or other professionals.

Regulatory reporting criteria are fairly similar between provinces and territories. There are three key areas where death investigation is required: (1) sudden unexpected death, (2) non-natural death, and (3) death in vulnerable populations. Approximately 15-20 per cent of all deaths are investigated. Death investigation is focused on the identification of preventive or corrective actions and the answer to the critical question: can something be learned here to prevent future deaths? In death by neurological criteria, the coroner or medical examiner can invoke authority prior to recovery. In donation after death by circulatory criteria the coroner or medical examiner cannot invoke authority until death is declared; however, they may be able to access some information. In both circumstances the coroner or medical examiner can place restrictions on the donation if there is belief that the recovery will negatively impact the death investigation.

Death Investigators are seeking answers to questions to fully understanding the circumstances of the death. In a death investigation when the focus is on "care" provided the framework for the approach will be "how does it relate to best practice? And is the practice documented?" It is important that information be readily available and that documentation is clear, thorough and complete. From the health record, the investigation will assess the provision of care against best practice guidelines, policies and procedures. If care deviated from the defined process the investigator will look to see if rationale was documented and reasonable clinical judgment utilized. If there is significant deviation from medical practice it may be identified as a learning opportunity. It could also be identified as a significant variation in which case the coroner or medical examiner could refer to the regulatory body or the police depending on the case and the findings.

In investigating a death in which organ and or tissue donation occurred, or will occur, the coroner or medical examiner may assess the following:

- is there a defined donation process and was it followed
- was the consent well documented
- in relation to consent was their capacity to provide consent, was it in the best interests of the patient and was there any undue influence on the consent
- was there alignment with clinical practice guidelines
- was there appropriate documentation by all involved
- was there an ability of care team partners to contribute and share their views
- was there redundancy; was review of care decisions undertaken by a second clinician

It is important to note coroners and medical examiners are not part of the circle of care - they are investigators. In coroner or medical examiner cases care teams and donation coordinators contact the coroner or medical examiner when moving forth to WLSM and deceased donation to inquire if there are any restrictions to donation. In rare cases the investigator may request some organs or tissues not be recovered as they will need to be examined as part of the investigation.

Recommendations from death investigations usually go to the quality management program within hospitals. It is important for these programs to disseminate the information and focus to process improvement.

Conclusion

The CCCS guidelines for WLSM provide expert guidance on the how and what of WLSM. This report and the publications that follow will provide users an immediately accessible means of implementing these guidelines into practice. As the end-user sees fit, tools to evaluate the capacity of their health system to offer this level of sophisticated EOL care can now be audited easily by applying the pre-designed tools. In settings where cDCDD is offered and/or provided, this toolkit and the guiding principles developed help meet the demand to achieve balance and clarity of goals in the management of the dying process.

Perhaps the clearest message that came from the workshop was the resolve that high quality EOL care is an expectation in the critical care unit and that the offering of the opportunity to donate to every family is critical in delivering that care. Moreover, the ability to integrate a profound sense of responsibility to the patient's comfort, to valuing and improving the family's experience, and to the donation process was viewed as an essential expert competency of the modern Canadian critical care unit.

All partners – the Canadian Critical Care Society, the Canadian Association of Critical Care Nurses, and the Canadian Society of Palliative Care Physicians – were fully engaged in the planning and execution of this workshop. While the output of this workshop may include publication and presentation in appropriate peer venues and journals, the value will be highest from the practical utility of the tools in critical care units where WLSM and cDCDD are practiced.

As full participants in the workshop, family partners were central motivators for improvement at each task. The focus provided by these gifted spokespersons allowed us a rare privilege to learn from every possible perspective of EOL care, and for this we have a different and better product. The family members encouraged us to invest in further research to learn how best to support families at EOL.

We could not have accomplished this work without the assistance of our partners from all disciplines who touch the ICU near the EOL and especially not without our family partners. We are indebted to all workshop participants for the frank discussion, honest exchanges, and open debates aligned with achieving the objectives of this workshop.

Appendix A: Acronyms and glossary of terms

Acronyms

CACCN	Canadian Association of Critical Care Nurses
CCCS	Canadian Critical Care Society
CCCS WLSM	Canadian Critical Care Society Guidelines for the Withdrawal of Life-Sustaining Measures
CSPCP	Canadian Society of Palliative Care Physicians
cDCDD	Controlled donation after circulatory determination of death also variably referred to as DCD donation after cardiac death or donation after cardio-circulatory death.
DD	Deceased Donation (organ and or tissues)
EOL	End-of-Life
ICU	Intensive Care Unit
MAID	Medical Assistance in Dying
MRP	Most Responsible Physician
NDD	Neurologic Determination of Death (Brain Death)
ODO	Organ Donation Organization
ODT	Organ Donation and Transplantation
PDSA	Plan-Do-Study-Act
RN	Registered Nurse
RT	Respiratory Therapist
SDM	Substitute Decision Maker
SW	Social Worker
WLSM	Withdrawal of Life-Sustaining Measures

Glossary of terms

Audit: A documented review of procedures, records and personnel functions to evaluate adherence to a predetermined documented standard or process.

Case Audit: This tool, used on a case by case basis, evaluates adherence to components of the WLSM guideline recommendations. Cumulative analysis of a series of cases of WLSM may identify opportunities for process improvement with the system (hospital).

Checklist: Prior to withdrawal of life support, there are many tasks to be accomplished by a variety of people. The checklist seeks to be a useful clinical tool used by the team of health care providers in organizing the tasks necessary to prepare for, and deliver, the withdrawal of life support.

Clinician-Patient Relationship: the moral foundation of health care and the starting point for treatment and shared decision-making.

Coercion/Undue Influence: *coercion* refers to the practice of forcing someone to do something non-voluntarily by use of force or threat; *undue influence* refers to a person feeling heavily pressured to make a decision, or a series of decisions, that they might not have chosen otherwise. While a decision under undue influence is technically voluntary, the person may report that they have no meaningful choice but to make the decision.

Conflict of Commitment/Divided Loyalties: A situation where a person has professional obligations (or loyalties) to a specific person that may be in conflict with loyalties the person has to another person. For example, the treating physician for the organ donor should not also be the treating physician for the potential organ transplant recipient; the physician's loyalties are divided. This is the main reason for separate clinical teams involved in clinical care, organ retrieval, and transplantation.

Conflict of Interest: A situation where the person is in a position to derive personal benefit from actions or decisions made in their professional capacity. For example, the treating physician stands to personally benefit from the death of the patient (e.g., the clinician may benefit financially or materially from the death), and so may not fulfill his or her professional obligations toward the patient as they might otherwise have done.

Consent: consent is a process; a discussion, not an event. The patient must first have the capacity to consent; it must be voluntary, and informed. That is, patients must have the ability to understand and appreciate the potential risks, benefits, and treatment options, likely consequences of the decision or lack of a decision. The consent must relate to the treatment, must be informed, given voluntarily and not obtained through misrepresentation or fraud.

Controlled Donation after Circulatory Determination of Death (cDCDD): This has also been referred to as donation after cardiac death or donation after cardio-circulatory death (DCD). cDCDD is considered when death is anticipated, but has not yet occurred, in an ICU or special care unit after a consensual decision to withdrawal life-sustaining therapy. Death is determined following cardiac arrest and the cessation of circulation. Before considering donation, the patient should be judged to have:

- a grievous irremediable injury or illness,
- dependence on life-sustaining therapy,
- intention to withdraw life-sustaining therapy, and
- anticipation of imminent death after withdrawal of life-sustaining therapy.

Dead Donor Rule: i) the removal of organs must not cause the patient's death; ii) the donor must be declared dead by either cardio-circulatory or neurological criteria before organs are retrieved.

Documentation Tool: A retrievable record of the actions of withdrawal of support (e.g. extubation, discontinuation of pressors) and the rationale for drug administration as tied to patient symptoms is documented in real time.

End-of-Life Care: to care for people in decline who are deemed to be terminal or dying in the foreseeable (near) future. In medicine, nursing and the allied health professions, end-of-life (EOL) refers to health care, not only of patients in the final hours or days of their lives, but more broadly care of all those with a terminal illness or terminal condition that has become advanced, progressive and incurable.

First-person Informed Consent for organ donation: consent for deceased organ donation is obtained directly from the capable potential donor. This is in contrast to the typical practice where authorization for deceased organ donation is sought from the legally appropriate representative, or family members.

Family Information Booklet: this resource will be designed for families of patients who are undergoing withdrawal of support in the ICU

Family Override/Family Veto: In circumstances where an individual has complied with the legal requirements for providing valid consent; refers to the practice of respecting a family's objection to organ/tissue donation over the deceased's validly executed consent

Grievous and irremediable medical condition: A person has a grievous and irremediable medical condition only if they meet all of the following criteria:

(a) they have a serious and incurable illness, disease or disability,

(b) they are in an advanced state of irreversible decline in capability,

(c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable, and

(d) their natural death has become reasonably foreseeable, taking into account all their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

Knowledge Translation: A dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of populations, provide more effective health services and products and strengthen the health care system.

Medical assistance in dying means (MAID)

(a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or

(b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.

Order Set: a standardized order set created to translate clinical practice guidelines to orders for physicians to initiate, and the team to follow, preceding, and at the time of, the withdrawal of support.

PDSA Cycle: is shorthand for testing a change by developing a plan to test the change (Plan), carrying out the test (Do), observing and learning from the consequences (Study), and determining what modifications should be made to the test (Act).

Policy: A set of policies are principles, rules and guidelines formulated or adopted by an organization to reach its long-term goals. Policies and procedures are designed to influence all major decisions, actions and activities that take place within the boundaries set by them.

Procedure: An established or official way of doing something.

Quality: The conformance of a practice with pre-established specifications or standards.

Quality Assurance: The policies and environment required to meet standards of quality care and provide confidence the care processes consistently conform to quality requirements.

Quality Control: Specific tests or tasks defined by the Quality Assurance Program to be performed to monitor care. These may include but are not limited to checklists, evaluations, inspection and audits.

Quality Improvement: A formal approach to the analysis of performance and systematic efforts to improve it.

System Audit Tool: A list of recommended requirements at a hospital level that would be put into place, in advance of cases of withdrawal of life support, to support professionals and families in the process, as determined by the guidelines. The "audit" would be of a hospital.

Withdrawal of life-sustaining measures: In patients with grievous irremediable or life limiting conditions, refers to the consensual decision (between the health care team, patient or surrogate decision maker) to stop life-sustaining measures (such as mechanical breathing support, artificial airways, cardiovascular support). WLSM is the most common event preceding death in intensive care units. WLSM may also be referred to as withdrawal of life-sustaining therapy or withdrawal of life support.

Appendix B: Participant Evaluation

Evaluation surveys were distributed at lunch on day 2 of the workshop and all participants were asked to complete surveys by end of day 2. Planning committee members and support staff (n=9) did not complete evaluations; there was a response rate of 86 per cent (25 of 29).

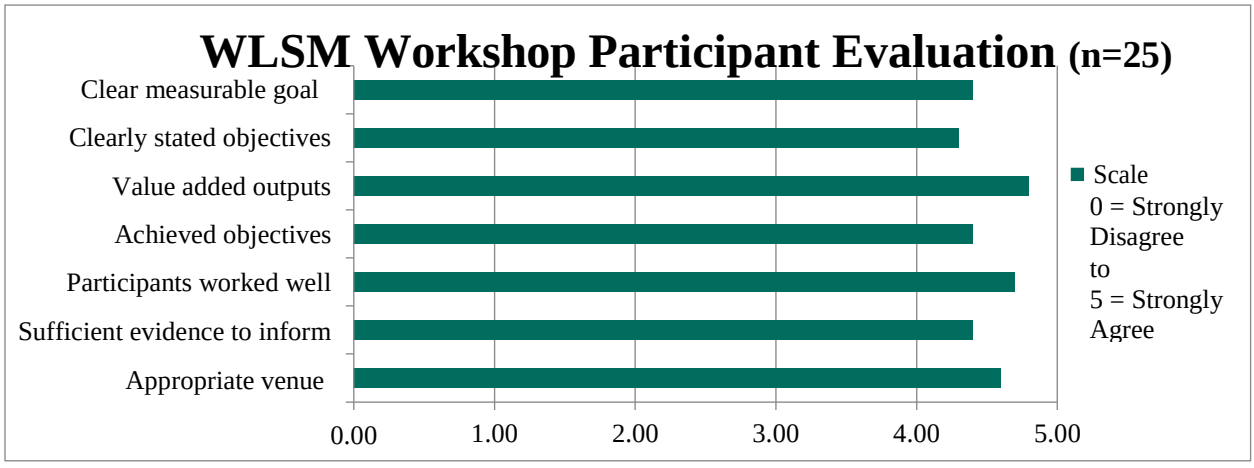
Evaluation Summary

Participants rated all key outputs of the workshop highly. The value of the workshop outputs and participant interaction received the highest ratings. Participants felt the workshop was well organized and facilitated. The participant mix and expertise was appropriate for the objectives and participants welcomed and acknowledged the value and role of family partners as full participants in discussions. Participants felt discussions were respectful, vibrant and enriching and that workshop outputs will be impactful. Participants identified actions to continue to advance this work and these will be incorporated in the final report.

Participants identified the following areas for improvement in future workshops. The need to increase racial diversity in the participant matrix including aboriginal representation. Participants indicated greater representation from nursing and spiritual care would have been welcomed. The provision of the draft tools prior to the workshop would have allowed more time for review and reflection. More time for reflection and table discussions was also identified as an opportunity for improvement.

Overall participant felt this was a very successful workshop indicating the outputs are of significant value, will impact and improve the provision of EOL care and are supportive of moving the outputs to implementation. Key comments relating to moving forth include; “You have set the standard for engagement”, “Don’t delay push ahead” and “Spread the word, share the documents”.

Figure 5: Evaluation Analysis



Appendix C: Workshop participants and affiliations

Planning Committee	
Dr. Andrew Healey (Chair)	Chair, Medical Director Trillium Gift of Life Network Hamilton ON
Ms. Manon Abud	Facilitator Hill + Knowlton Canada Toronto ON
Amber Appleby	Associate Director, Deceased Donation and Transplantation Canadian Blood Services Vancouver BC
Dr. James Downar	Critical Care and Palliative Care University Health Network and Sinai Health System Toronto ON
Dr. Michael Hartwick	Regional Medical Lead, Trillium Gift of Life Intensivist and palliative care physician, The Ottawa Hospital Assistant Professor, Divisions of Critical Care Medicine and Palliative Medicine, University of Ottawa Ottawa ON
Dr. Sean Keenan	Provincial Medical Director, Donation Services, BC Transplant Clinical Associate Professor, Critical Care Medicine University of British Columbia Vancouver BC
Jehan Lalani	Program Manager, Deceased Donation and Transplantation Canadian Blood Services Calgary AB
Jim Mohr	Senior Program Advisor, Deceased Donation & Transplantation Canadian Blood Services Halifax NS
Dr. Sam Shemie	Division of Critical Care, Montreal's Children Hospital Medical Advisor, Deceased Donation, Canadian Blood Services Professor of Pediatrics, McGill University, Montreal, QC
Participants	
Dr. Paul Boucher	Critical Care Physician, Foothills Hospital Calgary AB
Ms. Sarah Crowe	Clinical Nurse Specialist Critical Care Network Fraser Health and SMH & Jim Pattison Outpatient Care and Surgical Centre Surrey BC
Dr. Jesse Delaney	Critical Care / Palliative Care Scarborough and Rouge Hospital Scarborough ON
Mr. Nicolas El-Kada	CPE Coordinator Registered Psychotherapist, CASC Certified Teaching Supervisor Spiritual Care Services, The Ottawa Hospital-Civic Campus Ottawa ON

Mr. Edward Ferre	Interim Provincial Operations Director and Director, Program Development and External Relations, BC Transplant Vancouver BC
Dr. Alison Fox-Robichaud	Critical Care Hamilton Health Sciences President, Canadian Critical Care Society Hamilton ON
Ms. Torie Gusa	Critical Care Nurse Canadian Association of Critical Care Nurses (CACCN) Calgary AB
Dr. Laura Hawryluck	Critical Care University Health Network Toronto General Hospital, Toronto ON
Ms. Pamela Hughes	Critical Care Nurse Med, Surg, Neurosurgical Trauma Unit QEII Health Sciences Centre, Halifax NS
Dr. Dirk Huyer	Chief Coroner, Ontario Ministry of Community Safety and Correctional Services Toronto ON
Dr. George Isac	Anesthesiologist, Intensivist Vancouver Acute, Vancouver Hospital & Health Sciences Centre Vancouver BC
Mr. Michael Kampen	Patient Family Partner Father of Marshall Kampen Hamilton ON
Dr. Lisa Kenny	Assistant Professor of Medicine, Critical Care/Neuro-Critical Care Memorial University St. Johns NL
Ms. Sarah LaRoche	Respiratory Therapist Nova Scotia Health Authority Halifax NS
Florence Lebrun	Social Worker Royal Columbian Hospital Vancouver BC
Frances Moran	Patient Family Partner Father of Christopher Moran *A twitter feed which documented their story in real time was presented.*
Ms. Alison Morsley	Patient Family Partner Daughter of Ann Thelma Morsley Toronto ON
Dr. Laurel Murphy	Emergency Medicine Critical Care Medicine Nova Scotia Health Authority Halifax NS
Dr. John Muscedere	Professor of Critical Care Medicine Queen's University Intensivist Kingston General Hospital Kingston ON

Dr. Bojan N. Paunovic	Medical Director - WRHA Critical Care Co- Section Head - Critical Care Medicine Department of Internal Medicine Assistant Professor - Faculty of Medicine University of Manitoba Site Critical Care Lead & MICU Medical Director Health Sciences Center Winnipeg MB
Dr. Amanda Roze des Ordons	Critical Care Medicine, Palliative Care Clinical Assistant Professor University of Calgary Calgary AB
Dr. Aimee Sarti	Intensivist The Ottawa Hospital Ottawa ON
Dr. Christy Simpson	Head and Associate Professor Department of Bioethics, Faculty of Medicine Dalhousie University Halifax NS
Dr. Jenna Spring	Chief Medical Resident Toronto Western Hospital Toronto ON
Ms. Amanda Van Beinum	PhD Sociology Student/Health Researcher Children's Hospital of Eastern Ontario Ottawa ON
Dr. Brandi Vanderspank	Critical Care Nursing CACCN Assistant Professor School of Nursing, Faculty of Health Sciences University of Ottawa Ottawa ON
Ms. Tammy Vigliotti	Respiratory Therapist Providence Health care Vancouver BC
Dr. Matthew Weiss	Pediatric Intensivist Centre Mère-Enfant Soleil du CHU de Québec Québec QC
Ms. Kimberly Werestiuk	Manager of Patient Care Transplant Manitoba Winnipeg MB

Appendix D: Workshop agenda

Workshop Agenda for Wednesday June 7, 2017 (Day 1)

Sheraton Toronto Airport Hotel (801 Dixon Rd) – Collingwood Room

7:45 – 8:15	**Breakfast – Niagara Room**	
8:15 – 9:10	Welcome Remarks (10 min) – Canadian Blood Services – Canadian Critical Care Society – Workshop Chair	 Amber Appleby Dr. Alison Fox-Robichaud Dr. Andrew Healey
	Role of Family Partners (10 min)	Amber Appleby
	Around the Room (15 min)	Dr. Andrew Healey
	Process and Workshop Design (15 min)	Manon Abud
9:10 – 10:00	**Setting the Stage** – DCD: Historical Perspectives in Canada (15 min) – Challenge Address (25 min) – Q&A (10 min)	 Dr. Sam Shemie Dr. Andrew Healey
10:00 – 10:15	**Health Break – Collingwood Room**	
	Presentation	**Presenter(s)**
10:15 – 12:00	**CCCS Guidelines on WLSM** – Presentation (30 min) *with commentary from Dr. Jesse Delaney, Dr. Laura Hawryluck, Dr. Lisa Kenny* – Q&A (15 min) – Table Discussions (35 min) – Report Back to Plenary (25 min)	 Dr. James Downar
12:00 – 12:40	**Lunch – Niagara Room**	
	Presentation	**Presenter(s)**
12:40 – 14:30	**Family and Health care Professional Perspectives** – A Family Experience via Twitter (10 min) – Presentation (50 min) *with commentary from Michael Kampen, Alison Morsley* – Table Discussions (25 min) – Report Back to Plenary (25 min)	 Dr. Michael Hartwick Dr. Aimee Sarti
14:30 – 15:00	**Statement of Principles**	Dr. Sam Shemie
15:00 – 15:15	**Health Break – Collingwood Room**	
	Presentation	**Presenter(s)**
15:15 – 16:15	**Family Information Tool** – Background (5 min) *with commentary from Dr. Jenna Spring* – Table Discussions (30 min) – Report Back to Plenary (25 min)	 Dr. James Downar
16:15 – 16:30	Closing Comments	

Workshop Agenda for Thursday June 8, 2017 (Day 2)

Sheraton Toronto Airport Hotel (801 Dixon Rd) – Collingwood Room

7:15 – 7:45	**Breakfast – Niagara Room**	
	Presentation	**Presenter(s)**
7:45 – 8:30	Recap of Day 1 and Introduction to Day 2	Dr. Andrew Healey
8:30 – 9:00	**Coroner's Perspectives on Death Investigations and DCD**	Dr. Dirk Huyer
9:00 – 9:15	Q&A	
9:15 – 10:30	**Documentation Tool** – Background (10 min) – Table Discussions (45 min) – Report Back to Plenary (20 min)	Dr. Andrew Healey
10:30 – 10:45	**Break – Collingwood Room**	
	Presentation	**Presenter(s)**
10:45 – 12:00	**Order Set and Checklist** – Background (10 min) – Table Discussions (35 min) – Report Back to Plenary (30 min)	Dr. Andrew Healey
12:00 – 12:45	**Lunch – Niagara Room**	
	Presentation	**Presenter(s)**
12:45 – 14:00	**Case and System Audit** – Background (10 min) – Table Discussions (35 min) – Report Back to Plenary (30 min)	Dr. Sean Keenan
14:00 – 14:30	**Implementation/Accountability Agenda** *with commentary from Amber Appleby*	Dr. Sean Keenan
14:30 – 14:50	**Research Agenda** *with commentary from Dr. Jenna Spring, Dr. Jesse Delaney*	Dr. Brandi Vanderspank
14:50 – 15:00	**Reflections from Family Members**	Michael Kampen Alison Morsley
15:00 – 15:15	Closing Comments	Dr. Andrew Healey

Appendix E: Update to published literature review

Jesse W. Delaney, MD, James Downar, MDCM, MHS

Introduction

This is intended to serve as an update to a previously published review by Delaney and Downar[5], which was used to inform the development of national guidelines for the withdrawal of life support. The purpose of this update is to inform the development of a national quality assurance initiative led by Canadian Blood Services and the Canadian Critical Care Society to promote the adoption of these guidelines. The authors became aware that some papers may have been missed and so a broader search was undertaken.

Acknowledgments

We would like to thank Marina Englesakis for her help with the literature search. We would also like to acknowledge the contributions of Drs. Michael Hartwick and Andrew Healey, who helped to screen the articles for relevance, and Kerry Phillips for her help with retrieving articles for the review.

Methods

Search terms were elected based on terms that appeared frequently in articles from the initial review paper5. MEDLINE (1946 - Nov Week #4, 2016), ePub Ahead of Print / Medline In-Process & Other Non-Indexed Citations (Dec 1, 2016), EMBASE (1947 – Dec 1, 2016), Cochrane Central Register of Controlled Trials (October 2016), Cochrane Database of Systematic Reviews (2005 – Dec 1, 2016), and PubMed-NOT-Medline (1945 – Dec 4, 2016) were searched for studies in English. The same methodology was used here as in the previous review, the authors reviewed the search results and only articles judged to be relevant to WDLS were included. These articles were then searched for relevant references, and these studies were subsequently included. Inclusion criteria were intentionally broad and included any article discussing the process of WDLS in adult or pediatric critical care. Conference abstracts were excluded, but there were no other specific exclusion criteria. Each article was reviewed and content was abstracted[5].

Results

The search returned a total of 5556 references. After reviewing these references, a total of 61 were judged to be relevant and were included. A total of 2 additional relevant articles were found in the references and were subsequently included.

Preparation for WDLS

In this updated literature review the same themes emerged regarding preparation for WDLS, including: optimization of the care environment, education of family, organization of the care team, and preparation of the patient. Most of the literature provides recommendations which are very similar to the sentiments expressed in the previous review. However, there was some information that was sufficiently novel for it to warrant being highlighted.

Optimization of the Care Environment

- Counsell et al found that families appreciated use of a quiet room near to the patient. They also often identified easy access to resources such as food or a telephone as lacking[9].

Education of Family

- Kirchoff et al. investigated the use of 4 tailored messages in preparing families for WDLS. They found that families receiving the tailored messages were more satisfied with the information they received and they had a better understanding of the process and possible symptoms.[10]

Organization of the Care Team

- Several authors explored the role of nursing in WDLS and they suggested that nurse's role includes: helping to prepare families for WDLS; planning and management of the WDLS process; providing ongoing emotional support to the patient and family; facilitating family presence at the bedside and removing barriers to the patient.[11-13]
- Health care professionals, including nurses and respiratory therapists have indicated a desire to be more involved in discussions about WDLS, as well as in planning the process of WDLS[14]. Interdisciplinary rounds were also suggested as a method of obtaining broader input from the health care team.[15] However, one survey of critical care nurses found that most of them already attend family conferences where WDLS is discussed and greater than 10% of the respondents initiated these meetings.[16]

Preparation of the Patient

- While the literature generally suggests discontinuing all patient monitors, Counsell et al found that families often prefer that patient monitoring be left on.[9] It has also been suggested that that non-invasive monitoring of vital signs may continue as it might assist in titrating medications to maintain comfort.[17]

Monitoring Parameters

There was very little new information in the literature with respect to monitoring parameters. Most authors continued to recommend the use of physical signs and vital signs to detect pain, dyspnea, and agitation. Some authors recommend the use of standardized scales, particularly for the measurement of sedation/agitation.

There were two studies which used a novel approach to monitoring if symptoms.

- In one recent study evaluating a protocol for WDLS they created discomfort scales which were 5-point scales to measure movement, stridor, and "death rattle".[18]
- In a pilot study examining a terminal ventilator withdrawal algorithm the Respiratory Distress Observation Scale was used to measure patient respiratory comfort/distress. Stridor was also measured based on where the researchers could hear it from (head of bed, foot of bed, 10 feet from the foot of the bed).[19]

Pharmacologic Symptom management

The literature remains relatively consistent in its recommendations for the use of opioids to treat pain or dyspnea, and benzodiazepines to treat anxiety or agitation. The use of pre-emptive analgesia as well the use of bolus doses of medication, in addition to infusions, to rapidly achieve comfort were frequently mentioned in the literature.[17, 20-23] One author also advocated for the use of pre-emptive deep sedation for terminal extubation of awake patients, however this concept remains controversial and has been opposed by other authors.[23-25]

The recommended dose ranges for opioids and benzodiazepines continues to vary within the literature. There is also no evidence to support the use of one agent over another.

Other medications mentioned in the literature including neuromuscular blockers, propofol, antipsychotics, anticholinergics, furosemide, racemic epinephrine, corticosteroids and bronchodilators. There was an increased focus in the literature on the management of secretions post-extubation using anti-cholinergic medications, and on the management/prevention of post-extubation stridor using steroids and racemic epinephrine.[10, 16-18, 26-30] There was a general consensus that the use of neuromuscular blockers should be avoided during WDLS, but one observational study reported their use[26].

There was one case study describing the use of novel medications for WDLS.

- Noreika and Coyne describe a case of a patient who remained agitated on large doses of opioids, benzodiazepines, propofol, and dexmedetomidine. They were able to achieve comfort during WDLS using IV methadone, phenobarbital and ketamine. The authors attribute much of the significant symptomatic relief to the administration of ketamine.[31]

Withdrawing Life-Sustaining Therapies

There continues to be significant variation in WDLS reported in the literature. While many authors have strong opinions on the matter, there is no clear evidence to support a specific approach to WDLS. In particular, many authors have strong opinions on weaning of the mechanical ventilator and extubation despite the lack of evidence favoring a particular approach. Protocols for WDLS do exist within the literature, their implementation appears to be feasible and some observational studies report effective symptom control during WDLS.[18, 19]

The literature also highlights that the likelihood of undergoing WDLS may vary with both patient demographic factors and physician demographic factors.[32-34]

Additionally, concerns about WDLS in patients with neurologic injury were raised. This population often has single organ failure, their ability to experience suffering may be uncertain, and they often have a longer time to death after WDLS.[22, 33]

Bereavement

The literature contained very little about bereavement care other than to say the family should be supported.

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