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How is life support withdrawn in intensive care units: A narrative review

Jesse W. Delaney, MD [a], James Downar, MDCM, MHSc [b,c,*]

[a] Rouge Valley Health System, Toronto, Canada
[b] Division of Palliative Care, University of Toronto, Toronto, Canada
[c] Interdepartmental Division of Critical Care Medicine, University of Toronto, Toronto, Canada

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ABSTRACT

Purpose: Decisions to withdraw life-sustaining therapy (WDLS) are relatively common in intensive care units across Canada. As part of preliminary work to develop guidelines for WDLS, we performed a narrative review of the literature to identify published studies of WDLS.
Materials and methods: A search of MEDLINE and EMBASE databases was performed. The results were reviewed and only articles relevant to WDLS were included. Any references within these articles deemed to be relevant were subsequently included.
Results: The initial search identified 3687 articles. A total of 100 articles of interest were identified from the initial search and a review of their references. The articles were primarily composed of observational data and expert opinion. The information from the literature was organized into 6 themes: preparation for WDLS, monitoring parameters, pharmacologic symptom management, withdrawing life-sustaining therapies, withdrawal of mechanical ventilation, and bereavement.
Conclusions: This review describes current practices and opinions about WDLS, and also demonstrates the significant practice variation that currently exists. We believe that the development of guidelines to help increase transparency and standardize the process will be an important step to ensuring high quality care during WDLS.

1. Introduction

When patients die in the intensive care unit (ICU), it usually follows a decision to limit or withdraw life-sustaining therapy (WDLS) [1]. Many studies have examined the factors that influence this decision-making process [2–9], and there are published guidelines to help clinicians decide when and how to make this decision [10,11]. However, once the decision regarding withdrawal of life-sustaining therapy has been made, there is little evidence and no published guidelines to help clinicians decide how to proceed.

Withdrawing life-sustaining therapy can be a complicated procedure. Clinicians have a medical obligation to ensure that patients are kept comfortable, an ethical obligation to avoid prolonging the dying process, and a legal obligation to avoid inappropriate shortening of the dying process. It is not always easy to meet these obligations, and the consequences can be significant [12]. Poor symptom management at the end of life is bad for the patient, family, and caregivers alike. However, shortening the dying process can lead to legal consequences as well as loss of trust among the public, who may perceive that physicians are deliberately and inappropriately hastening death for reasons other than patient comfort [13]. Orders for WDLS can be unclear and inconsistent [12,14,15], and nurses feel that families could be better prepared for the process [16].

WDLS guidelines could help ICU clinicians meet their medical, ethical, and legal obligations, while providing increased clarity for physicians, nurses, and allied health care providers [17–19]. As part of preliminary work to develop guidelines for WDLS, we performed a review of the literature to identify published studies of WDLS. We began the process with the knowledge that there was unlikely to be high-level evidence to guide WDLS, so we chose to perform a narrative review in an attempt to synthesize the observational work and expert opinions on the topic.

2. Materials and methods

An initial search was performed to identify relevant articles. Keywords and references from these articles were then used to inform a search. MEDLINE (1946 to week 2 of March 2014) and EMBASE (1974 to October 10, 2013) were searched for studies in English using the terms passive euthanasia, withdrawal, termination, life support, life-sustaining, ventilation, artificial respiration, and resuscitation (see Appendix A for full search strategy). The authors reviewed the

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Abbreviations: WDLS, withdraw(al) life-sustaining therapy; DCD, donation after cardiac death; ICU, intensive care unit; BPS, Behavioral Pain Scale; CPOT, Critical Care Pain Observation Tool; RDOS, Respiratory Distress Observation Scale; CPR, cardiopulmonary resuscitation; LTACH, long-term acute care hospital.

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[*] Corresponding author.
E-mail address: james.downar@utoronto.ca (J. Downar).

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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. The information was then grouped into the following common themes: preparation for WDLS, monitoring parameters, pharmacologic symptom management, withdrawal of life-sustaining therapies (including withdrawal of mechanical ventilation), and bereavement.

3. Results

Our initial search identified 3687 articles. A review of the titles and abstracts identified 53 articles of interest. A further 46 articles were identified from the reference sections of these articles, and included in the review. In total, we identified 1 randomized controlled trial, 3 nonrandomized interventions, 26 observational studies, 14 qualitative studies (surveys or interviews), 3 case reports, 23 reviews, 9 guidelines, and 20 opinionated editorials.

3.1. Preparation for WDLS

Many articles discuss issues pertaining to preparation for WDLS. These articles primarily present expert opinion on the topic, but there is a small amount of qualitative data to help guide practice. Common themes emerge including suggestions around the care environment, education of family, organization of the care team, and preparation of the patient (Table 1).

Regarding the care environment, multiple articles suggest moving the patient to a separate area or isolated room, or drawing the curtains in an open unit [11,12,20–24]. Some suggest providing music and allowing cultural or religious death rituals to provide an appropriate emotional environment for WDLS [12,20,21,23–26]. Increased privacy is associated with increased family satisfaction with the process of WDLS [27]. There is broad agreement that visiting restrictions should be liberalized, at least to the extent that is does not interfere with the care of other patients [11,12,20–25,28].

Many authors feel that it is important to educate family members prior to WDLS [10–12,20–25,29–35]. Family members report a higher degree of satisfaction with WDLS when they received a good explanation of WDLS and had an opportunity to participate in the discussion and ask questions [27]. Authors place particular emphasis on explaining the dying process in understandable terms; preparing family members for the signs and symptoms that they may witness and outlining how they can be managed, and educating family members on breathing patterns at the end of life (often referred to as “agonal” breathing) and noisy breathing from airway secretions (sometimes referred to as the “death rattle”) [25,31]. Many authors also recommend discussing the uncertainty of the time of death after WDLS. Patients may survive for hours or days after WDLS, and potentially may need to be transferred to another care environment. Rubenfeld [22]recommended directly addressing the difficulty a family might experience during WDLS when the dying process is longer than expected. He suggests that simple comments such as “It's hard to have to wait like this, isn't it?” may be effective in broaching the topic.

Family members require ongoing support from the care team through the process of WDLS. Many authors recommend involvement of spiritual care providers to help prepare and support families during WDLS [11,12,20–25,28,31]. In one survey, almost half of family members of patients who had undergone WDLS identified faith or spirituality as a significant and reassuring aspect of the hospital stay [28].

The care team should plan how WDLS will proceed and which team members will be involved. Commonly mentioned team members included the bedside nurse, a physician, and a respiratory therapist. Multiple authors suggest that the respiratory therapist should be at the bedside, along with an attending physician or fellow with a syringe of comfort medication, to ensure comfort during weaning of mechanical ventilation and extubation [12,25,26].

Table 1
Summary of themes

Preparation for WDLS	All activities done prior to WDLS in order to improve the experience for both patients' and families. • Optimizing the care environment • Education of family • Organization of the care team • Preparation of the patient
Monitoring parameters	The use of vital signs, physical signs, or tools to assist in the diagnosis of pain, dyspnea, agitation, and delirium during WDLS
Pharmacologic symptom management	The use of medications such as opioids, benzodiazepines, antipsychotics, and anticholinergics to manage symptoms, and the avoidance of neuromuscular blockers
Withdrawing life-sustaining therapies	The process of discontinuing life-sustaining therapies including blood products, hemodialysis, vasopressors, mechanical ventilation, total parenteral nutrition, antibiotics, and intravenous fluids. Special attention was given to the withdrawal of mechanical ventilation including terminal weaning vs terminal extubation.
Bereavement	Care of the patients' family both during and after WDLS in support of their grieving process

Multiple authors suggest that all unnecessary medications should be stopped. Monitoring devices can also be discontinued and monitors turned off, as they are not necessary to assess symptoms and may be distracting to family members [11,19,22,23,25,26]. Rubenfeld [22] suggested removing all tubes, lines, and drains that can be removed without discomfort, but leaving tubes in place whose removal might lead to obstruction (eg, foley catheters, biliary drains) and intravenous lines for medications.

There was general support in the literature for discontinuation of intravenous fluids and artificial nutrition. Authors suggest that discontinuing these therapies generally does not cause discomfort, whereas continuing them may in fact lead to discomfort. Several authors mention the controversial nature of these decisions and they generally recommend taking time to counsel the family [11,21,23,24,26,36].

3.2. Monitoring parameters

Many different parameters are used to manage patients during WDLS, but no assessment score, tool, or monitoring parameter has been specifically assessed or validated for use during WDLS. Recent guidelines have been published for the management of pain, agitation, and delirium in adult ICU patients [37]. These guidelines do not specifically address WDLS, but they recommend the use of validated assessment scales for pain, agitation, and delirium (Table 2).

For the assessment of pain during WDLS, the Behavioral Pain Scale, Critical Care Pain Observation Tool, or the Pain Assessment Behavior Scale are most frequently recommended [11,32,38,39]. Two authors suggest using a pain behaviors checklist, based on the specific behaviors that correlate with patients' self-report of pain. These behaviors include grimacing, rigidity, wincing, shutting of eyes, clenching of fist, verbalization, and moaning [32,38]. Mularski et al [32] also suggest the use of multiple proxy raters, including family members in the assessment of pain.

Only one tool was suggested for the assessment of dyspnea during WDLS—the Respiratory Distress Observation Scale [40]. However, there are no studies demonstrating its use in WDLS.

Although many authors discuss agitation, few discuss the specifics of assessing agitation during WDLS. The Bizek Agitation Scale was used in one study [41]. Similarly, no publications identify a specific delirium assessment tool for WDLS.