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## Process of Withdrawal of Mechanical Ventilation at End of Life in the ICU:

### Clinician Perceptions

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### Abstract

**BACKGROUND:** Nearly one-quarter of all Americans die in the ICU. Many of their deaths are anticipated and occur following the withdrawal of mechanical ventilation (WMV). However, there are few data on which to base best practices for interdisciplinary ICU teams to conduct WMV.

**RESEARCH QUESTION:** What are the perceptions of current WMV practices among ICU clinicians, and what are their opinions of processes that might improve the practice of WMV at end of life in the ICU?

**STUDY DESIGN AND METHODS:** This prospective two-center observational study conducted in Boston, Massachusetts, the Observational Study of the Withdrawal of Mechanical Ventilation

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**Author contributions:** C. R. F. had full access to all data in the study and takes responsibility for data integrity and accuracy of analyses. A. F. B., A. J. R., and C. R. F. contributed substantially to the study design, analysis, interpretation, and writing of the manuscript. A. C. N., R. M. S., M. L. C., Z. C., D. B. W., and S. L. M. contributed substantially to the study design, interpretation, and critical review of the manuscript.

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(OBSERVE-WMV) was designed to better understand the perspectives of clinicians and experience of patients undergoing WMV. This report focuses on analyses of qualitative data obtained from in-person surveys administered to the ICU clinicians (nurses, respiratory therapists, and physicians) caring for these patients. Surveys assessed a broad range of clinician perspectives on planning, as well as the key processes required for WMV. This analysis used independent open, inductive coding of responses to open-ended questions. Initial codes were reconciled iteratively and then organized and interpreted using a thematic analysis approach. Opinions were assessed on how WMV could be improved for individual patients and the ICU as a whole.

**RESULTS:** Among 456 eligible clinicians, 312 in-person surveys were completed by clinicians caring for 152 patients who underwent WMV. Qualitative analyses identified two main themes characterizing high-quality WMV processes: (1) good communication (eg, mutual understanding of family preferences) between the ICU team and family; and (2) medical management (eg, planning, availability of ICU team) that minimizes patient distress. Team member support was identified as an essential process component in both themes.

**INTERPRETATION:** Clinician perceptions of the appropriateness or success of WMV prioritize the quality of team and family communication and patient symptom management. Both are modifiable targets of interventions aimed at optimizing overall WMV.

### Keywords

critical care; palliative care; clinician distress; extubation; end-of-life care; withdrawal of mechanical ventilation

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Nearly one-quarter of all Americans die in the ICU, and many of these deaths are anticipated and occur following the withdrawal of mechanical ventilation (WMV).<sup>1,2</sup> Short- and long-term psychiatric sequelae in family members or caregivers in the ICU are becoming increasingly well recognized. The family members of ICU patients are vulnerable to depression, anxiety, and posttraumatic stress disorder, a constellation labeled as post-intensive care syndrome-family.<sup>3,4</sup> The death of a patient in the ICU can also have profound implications for physicians, nurses, and other health care professionals. As with post-intensive care syndrome-family, moral distress among team members in the ICU is beginning to be recognized and examined in the critical care literature.<sup>5</sup>

The anticipated nature of many of the deaths involving WMV presents an opportunity for thoughtful guidance and best practices around care for patients who undergo this procedure.<sup>6</sup> Many critical care practice guidelines for end-of-life care are based on expert opinion.<sup>7-9</sup> As a result, practices vary widely, and patient distress is both common and underrecognized.<sup>10-17</sup> The lack of evidenced-based practice guidelines and inadequacy of current practices not only has the potential to exacerbate patient and family distress but all contribute to the stress and burden experienced by clinicians involved in the WMV process. To address this gap, qualitative data from a large prospective study of WMV at the end of life in the ICU setting (Observational Study of the Withdrawal of Mechanical Ventilation [OBSERVE-WMV]) were analyzed with the objective of understanding ICU clinician perspectives on processes that best mitigate distress during WMV at end of life.

## Study Design and Methods

The institutional review board at Beth Israel Deaconess Medical Center provided approval and oversight of OBSERVE-WMV. Enrolled patient participants were aged ≥ 18 years, endotracheally intubated, and receiving mechanical ventilation in an ICU, with a decision made to transition to comfort-focused care at end of life via WMV. As part of the broad study, quantitative data were collected to characterize patients' symptoms and treatment provided during the WMV process. The current report focuses on the portion of the OBSERVE-WMV study in which open-ended items from in-person surveys with ICU clinicians caring for these patients determined clinician perspectives and experiences of the WMV process.

Participants were recruited from a mixed group of 12 ICUs (neurological, medical, surgical, trauma, cardiac, and cardiovascular surgical) at Beth Israel Deaconess Medical Center and Brigham and Women's Hospital in Boston, Massachusetts. Clinicians (physicians, advanced practice providers [nurse practitioner or physician assistant], respiratory therapists, and nurses) were eligible to participate if they were a team member directly caring for a patient for at least 1 h during WMV at the end of life in the ICU. Eligible clinicians were identified by research staff through regular communication with the ICU team. This consisted of daily in-person visits or telephone calls to individual ICUs to identify patients who may be undergoing WMV at end of life.

Details of the OBSERVE-WMV observational study, in which this qualitative analysis was a component, are as follows: once a patient was enrolled in the observational study, standard symptom assessments (eg, pain, dyspnea, agitation) were obtained by the ICU nurse for 1 h prior to WMV, and at standard time intervals until the death of the patient or 3 h following WMV; and patient demographic, critical illness severity, and post-WMV management data were abstracted from the electronic medical record after death. Following this process, the physician or advanced practice provider, respiratory therapist, and ICU nurse caring for the patient were considered "eligible clinicians" and were invited to participate in the in-person survey portion of the study. Therefore, there were three eligible clinicians associated with each patient enrolled in the study. Details of the study were explained, and written or verbal informed consent was obtained from clinicians agreeing to participate.

Surveys were conducted by study staff (A. C. N., C. R. F.) either in person or via secure video conference from January 13, 2021, until March 28, 2022. In-person interviews were conducted in a separate space in the ICU at the time of WMV thought to be convenient per the clinician. If interviews could not be conducted at the time of WMV, a time was arranged to complete the interview within 7 days. Survey completion required 10 to 20 min depending on response length from participants. Responses were entered verbatim directly into a secure REDCap database by study staff or participants depending on interview format (in-person or video conference, respectively). Interviews were not recorded due to real time capture of data.

## Survey Instrument

The survey instrument was developed by a multidisciplinary group of experts (e-Appendix 1 lists the expert advisory panel). Questions underwent iterative development among experts, reviewed/piloted by ICU clinicians (Carter Glenn, registered nurse [RN]; Lorna Caffery, RN) for accuracy, and referred back to the expert panel for further refinement.<sup>18</sup> This qualitative analysis focused on open-ended questions from the larger survey instrument. The full survey instrument (e-Appendix 2) covered several domains: Likert scale questions assessing adequacy of symptom control and other aspects of clinical management, family member involvement, team member planning and participation, multiple open comment fields, and clinician demographic characteristics. Two open-ended questions were qualitatively analyzed for this project: (1) What could have improved the planning process for withdrawal of mechanical ventilation at the end of life for this particular patient? and (2) What might improve the process of withdrawal of mechanical ventilation at the end of life in the ICU? These fields were chosen because they most closely aligned with the research question focused on the WMV process.

## Analysis

A descriptive analysis of demographic characteristics of the care team included birth year, clinical training background, number of years in practice, and number of years practicing in the ICU. Qualitative analysis was performed by two members of the study team (A. F. B., a surgical resident; A. J. R., a health services researcher with qualitative methods experience) who independently conducted open, inductive coding of 20 responses and met to reconcile codes and compile an initial codebook. The entire study team then met to review the codebook. This process was repeated three additional times until a final codebook was agreed upon and coders achieved consensus in interpretation of codes. As part of the final coding scheme, codes were accompanied by a valence code (WMV process appropriate or WMV process inappropriate), if applicable. If there was no clear positive or negative connotation, we did not assign a valence.<sup>19,20</sup>

Two members of the study team (A. F. B., A. J. R.) then each coded one-half of the total responses. Responses were then sorted by code in Microsoft Excel (Microsoft Corporation) and reviewed for interpretation (A. F. B., A. J. R.) using a thematic analysis approach.<sup>21</sup> Themes were refined by the entire study team through discussion. All completed responses were coded for the final analysis.

## Qualitative Rigor

Rigor was safe-guarded by careful consideration of data credibility, dependability, confirmability, and transferability.<sup>22</sup> Credibility was achieved through prolonged engagement. The principal investigator and primary data collector (C. R. F. and A. C. N.) both spent substantive time in the ICU, and the primary data collector (A. C. N.) was present during WMV, making observations prior to survey collection. Survey questions were reviewed/piloted by ICU clinician staff (Carter Glenn, RN; Lorna Caffery, RN) prior to further iterative review of the study team comprising experts in the field of critical care medicine, surgery, and health services research/methods. Dependability was established through an audit trail of notes from the coding process in which codebook versions and

any changes to the coding scheme were documented. Independent coding, line-by-line comparison during analysis ensured consistent interpretation along with regular research team meetings to discuss findings. Confirmability was achieved through a multidisciplinary team (discussed earlier), with attention to reflexivity brought by each team member's professional role (eg, survey questions were initially developed by the principal investigator and other physicians and then piloted by ICU RN staff). Data were triangulated by comparing open coded responses with quantitative survey items and observations made by the primary data collector (A. C. N.) during research team meetings. Transferability was improved by purposive sampling of participants according to role and setting.

The study adhered to the American Association for Public Opinion Research guidelines for surveys.<sup>23</sup> The Standard for Reporting Qualitative Research checklist is included as Appendix 1.<sup>24</sup>

## Results

Among 456 eligible clinicians, 312 surveys were completed with clinicians caring for 152 patients with complete data of 160 enrolled who underwent WMV (Table 1). Of these, 140 surveys were completed by bedside ICU nurses (RN, Master of Science in Nursing); 14 were completed by advance practice providers (physician assistants, nurse practitioners); 66 were completed by respiratory therapists; and 100 were completed by physicians. Eligible clinicians were identified by patients undergoing WMV, resulting in repeat clinician surveys among 50 (16%) participants. There were 33 respiratory therapists (RTs), 15 RNs, and two nurse practitioners who were interviewed more than once. Mean ( $\pm$  SD) age of clinician participants was  $38 \pm 11$  years; they averaged  $10 \pm 9.2$  years of practice experience and  $8 \pm 9.8$  years within critical care.

In response to the two open-ended questions about process improvement, two main domains of responses emerged from care teams involved in WMV: nonclinical communication and preparation for clinical treatment during and following WMV (Fig 1). These two process components interacted with and relied upon each other but differ in the ways they are able to be protocolized and standardized.

### Communication

The communication domain included the following elements: the treating team (including input from consultants), the family and patient response, and the need for team member support. Elements of the team plan associated with a good WMV process were a clearly defined, agreed upon plan derived with input from and communicated to all members of the team (Table 2).

“I think having a clear concise plan outlined with the care team prior to implementing measures is most important, while maintaining an open mindset after withdrawing ventilation and addressing patient's comfort needs one by one.”

[RN; 4 years' critical care experience]

Important elements of the team plan and supporting quotations are provided in Table 3. These elements included a clear decision to transition to a focus on comfort measures,

timing of WMV, a determination of who would be at bedside (ICU nurse) and who would be available if needed (physician, respiratory therapist, and pharmacy support), and details of clinical management (discussed in the following text).

“Always have a good plan (including meds and correct orders) that you have discussed with the interdisciplinary team and verify that everything is in place and ready to go prior to extubation...”

[RN; 0.25 year critical care experience]

“Having a team huddle prior to withdrawal of mechanical ventilation is effective in getting everyone involved on the same page with a direct protocol in place including what to say to the family and preference of medication.”

[no degree or years of experience provided]

Even more important than the specifics of the team plan was a joint understanding about both the decision to withdraw ventilatory support and the determination as to how the removal of ventilatory support would be conducted.

“Establish a plan ahead of time and include a protocol for the pathway to extubation that includes: med order set, timing of intervals for vent and/or med weaning, as well as overall timing for the extubation process that includes [input from] social work, clergy, RT, RN, [doctor of medicine (MD)], family, etc.”

[RN; 3.75 years' in critical care]

The role of the consulting teams (eg, subspecialists in cardiology, neurology) played a smaller role in ICU clinician's perceptions of teamwork, team dynamics, and the team plan; a lack of support from them, however, was seen as a cause of delays in proceeding with WMV.

“I am very angry with our [redacted] service. The patient had an [automatic implantable cardioverter defibrillator] as well as a pacer; we asked to have both turned off. They came and turned off the [automatic implantable cardioverter defibrillator] but did not turn off the pacer. We called them multiple times and they refused. This [ie, appearance of cardiac electrical activity after circulatory arrest] was distressing to everyone.”

[MD/Doctor of Osteopathic Medicine; 18 years in critical care]

The team plan exists in an iterative, dynamic relationship with the needs of the patient and family.

“I think WMV at end of life, or end of life in itself is better handled when practitioners are able to come to terms with end of life. A better understanding of it allows everyone to be able to support family and brings better care to the patient. Experience/education and support of new nurses [who have not yet experienced an end-of-life] situation [will result in] a better outcome.”

[RN; 15 years in critical care]

A good process was almost uniformly seen as one in which the family was well informed about and understanding of the terminal state of their loved one and the nature of the WMV process.

“Preventative/prophylactic meds give prior to extubation to minimize symptoms in anticipation, instead of waiting for symptoms to arise. Can be very difficult for families to see their loved ones in any distress, even if just for a few moments while we are getting meds to give. [There should be] more education to families prior to extubation.”

[RN; 11 years' critical care experience]

In addition, it was important that the family's preferences and beliefs were clearly understood and respected, and that the coordination of timing with family to facilitate their presence during WMV was considered.

“It would be great to create a pathway to guide practitioners [through the process], but it is also important to [recognize], value, [and respect] cultural differences/beliefs, etc., at such an important moment in the patient's and family's life.”

[RN; 15 years' critical care experience]

“Timing might be important in these cases, particularly for improving family coping. Having a preset time where the code status is changed seems to help.”

[No degree given; 1.5 years' critical care experience]

Good communication between the family and care teams was critical to ensure that the family's preferences were incorporated into the plans, thereby facilitating a good, peaceful experience for the family of their loved one's death and the perception that the WMV process went appropriately.

“I think sometimes they hear us say removing the tube will make them comfortable but there isn't the realistic expectation that there may be some symptoms that will arise that can be quickly treated.”

[RN; 11 years' critical care experience]”

These preferences and needs, as well as specific issues around timing of the family's presence, sometimes created stress for the family or introduced the need for the care team to adapt to a sudden change in the WMV plan; nonetheless, the presence of family and the experience of the family was still considered the central element for achieving what was perceived as a successful WMV.

“Timing was challenging because of the family's decision to spend more time with the [patient] and concentrate on his comfort. Despite the fact that this made the time of WMV at shift change, both day and night nurses worked together through the extubation, the [respiratory therapists] traded off, and the process went relatively smoothly.”

[RN; 17 years' critical care experience]

Attention to the family preferences and the ability to anticipate and prepare for the family's experience was perceived as instrumental to the perception that the family's preferences and



experience were respected. Communication between family and team was bidirectional; the two constantly informed one another and led to adjustments in the plan.

“Consistent team huddles with all members of the interdisciplinary team might greatly improve this process. These huddles should happen prior to approaching the family to discuss WMV as well as immediately prior to extubation. Having palliative care more involved in the meetings discussing WMV at end of life and then having [a] palliative check-in the day of the planned WMV would help.”

[RN; 2 years' critical care experience]

Open, clear communication, with frank goals of care conversations between care team members and family, was essential to facilitating this component of the WMV process.

“In my experience I feel that having end-of-life discussions with the patient and their loved ones early on in their stay is crucial in keeping the patients comfortable at the end of their lives because we would then know what he/she would want or not want done at the end of their life.”

[Master of Science in Nursing; 2 years' critical care experience]

“Informing family of [the] procedure and setting expectations in advance; asking for input from family, patient (if appropriate), and other staff as to what they believe would be the ideal circumstance and what would the [patient] want.”

[nurse practitioner; 22 years' critical care experience]

## Preparation

Preparation and planning were seen as central to the success of the clinical management of the patient during WMV, and therefore to the success of the team in caring for the patient and their family during this event.

“Always have a good plan (including meds and correct orders) that you have discussed with the interdisciplinary team and verify that everything is in place and ready to go prior to extubation. Always oral/[endotracheal] suction first. Always have medications on hand and ready to give (for pain/anxiety/secretions, etc.). Always have a few sets of hands to optimize positioning or so that someone's able to leave the room to get anything you might need.”

[RN; 0.25 year critical care experience]

Team discussion of anticipated symptom management was a key component of clinical planning for WMV.

“Assuring all members of the team are involved and on the same page; for example, pharmacy with correct medications, doctors with correct orders.”

[rRT; 5 years' critical care experience]

Bedside ICU nurses expressed the need for general principles of symptom management during WMV in addition to specifics of the team plan for the individual patient.



“Have all medications ready and prepped before starting the end-of-life process to optimize the patient’s comfort.”

*[no degree or experience information provided]*

“More sedation.”

*[RT; 13 years’ critical care experience]*

It was deemed important to anticipate a variety of outcomes regarding the patient response to extubation, and many expressed a desire for greater protocolization—especially through order sets—for this aspect of the WMV process. This included a desire to have all medications that might be required to ensure patient comfort at the bedside and immediately available for use to optimize the WMV process and family experience.

“Have the order sets in the computer pre-withdrawal of care or somehow initiate once [comfort measures only] decision made. Pharmacy verification of medications can cause delay in patient comfort. Palliative care order set [is] very helpful including all [drips] and [pro re nata] medications available for patient when needed instead of chasing down order and patient having to wait.”

*[RN; 7 years’ critical care experience]*

Early bedside preparation for and control of pain and agitation with adequate analgesia and sedation prior to initiating the WMV process were seen as essential to setting the stage for adequate symptom control during and following WMV; the majority of those expressing this opinion were ICU nurses.

“Encourage continuous drips for analgesia and sedation. Have [pro re nata] meds readily available every five minutes.”

*[RN; 24 years’ critical care experience]*

“Premedicating for pain and secretions prior to extubation, making sure team and respiratory is ready at the appointed time with better communication and coordination with all members.”

*[RN; 3 years’ critical care experience]*

For many staff, having a plan for the timely delivery of unanticipated medications was as important as, or more so, than determination of what was needed in advance given the high probability of unexpected issues. Delays in physician placement of orders was identified as a particular problem for the WMV process. Having the ability to place orders as needed following WMV was seen by multiple respondents as enabling the ability to salvage an otherwise inappropriate WMV process.

“Readiness and availability of team members such as respiratory therapist and intern MD to move forward with weaning process and adjustment of analgesic medications. Team members were unable to promptly respond to ICU RNs’ pages/calls due to responsibilities with other patients at this time. If communication had been more prompt, the process would have been more streamlined. However, the patient did not experience any adverse effect from this delay, and the family was satisfied with the experience.”

[RN; 4 years' critical care experience]

### Team Member Support

Team member support was deemed essential to each component of the WMV process, including emotional responses that follow the death of the patient.

“It all boils down to communication and preparation. No nurse should be left unsupported or not equipped with exactly what’s needed to keep the patient comfortable, and I would like to be sure that NEVER happens. Communicate, plan together, then see it through before extubation begins.”

[MD/Doctor of Osteopathic Medicine; 18 years' critical care experience]

Beginning with the team plan, team members need to feel included in the decision-making process. Especially for less experienced care team members, support in the form of education about the WMV process was important to assuage concerns that they were “euthanizing” patients.

“Having the periodic assessment symptom scales used in this study was very helpful in determining if/when/how much extra sedation/analgesia was needed. It is also a nice way to ‘justify’ these actions. Some caregivers are fearful of being seen as ‘euthanizers,’ and hence, undertreat the symptoms. Having an easy, straight-forward end-of-life/terminal extubation tool ... would be helpful.”

[RN; 10 years' critical care experience]

Support for team members in the clinical preparation and planning phase was centered on the immediate availability of assistance for the bedside nurse in the form of order placement and pharmacy fulfillment for medications, the presence of a senior physician (even if only briefly, to check in) after WMV to help the nurse assess symptom management and other needs, and availability of RTs to help manage airway concerns following WMV.

“Having more RT support and involvement pre- and post-extubation. RT being able to assist with pulmonary hygiene. I feel comfortable managing pain and sedation, however, seeing a dying patient in respiratory distress is a big challenge for me. I rely on the RT to help determine and implement the best interventions to alleviate any suffering.”

[RN; 15 years' critical care experience]

Following WMV, team member support took the form of debriefing after the patient’s death and provision of spiritual and social support for staff members as needed.

“End- of life deserves as much finesse as saving a life. If we mentored young nurses or new ICU nurses and MDs through this, I believe it would make a dramatic difference for all involved. Families, patients, and care teams.”

[RN; 9 years' critical care experience]

## Protocolization

The desire for discrete treatment protocols were not deemed incompatible with the need for individualization and adaptability.

“(1) More specific guidelines for premedication (ie, what are the goals pre-WMV? Is it respiratory rate, degree of wakefulness, etc.). (2) Having more medications on hand for the ‘what ifs.’”

[RN; 12 years’ critical care experience]

Those who expressed a preference for individualization and adaptability articulated the desire to keep the patient and family needs at the center of the plan and for the flexibility to adapt to the specifics of a given clinical and social situation. This flexibility and adaptability primarily related to the extra-clinical, communication-based domains of the team plan and family preferences/experience.

“Every patient is different. There’s no actual way of knowing what could be better for the patient after withdrawal of mechanical ventilation. I feel like keeping them comfortable and making sure they’re not in distress is what we already do.”

[RN; no years of experience provided]

“Make sure to always have a conversation beforehand with multiple team members on what the plan is and what we will do if the original plan does not work well for the patient. Keep the family involved in this plan. If family is present tell them what we look for to see if a patient seems to be in pain or distress so that they can be involved in keeping their family member comfortable and since we are not always in the room. I think that communication between all the members to remain open and to remember that not all plans work properly for every patient, and we made need to go away from specific order sets for patients.”

[RN; 2 years’ critical care experience]

Those who expressed a desire for greater protocolization largely focused on medication, airway, and symptom management of the clinical care during WMV. Order sets, as well as standardizing the team members available or directly involved, were specific suggestions offered for protocolization measures that would facilitate the WMV process.

“An order set with general orders and medications for how to standardize the process for terminal extubation. In addition, communication with the team and family prior to extubation helps to improve the process for the patient, team, the bedside nurse, and the family as well.”

[RN; 5 years’ critical care experience]

“Educating staff on use of a standard protocol for comfort care ... that includes parameters/guidelines for when and how much to medicate.”

[RN; 20 years’ critical care experience]

“Having a template to follow as exists for other procedures.”

[RN; 22 years’ critical care experience]

Those who expressed a desire for greater protocolization, as opposed to emphasizing the need for individualization and adaptability, were almost uniformly team members with more critical care experience.

## Discussion

This large qualitative analysis of multidisciplinary ICU clinicians' perceptions of current WMV practices among ICU clinicians identified two broad domains for processes that facilitate alleviation of distress following WMV: communication and planning. First, the communication domain knits together the members of the care team internally as well as with the patient and their family into a dynamic, iterative relationship throughout the WMV process. All stakeholders need to be engaged and re-engaged as preparations and events demand; changes or concerns on the part of one party often necessitate adaptation and adjustment. The second domain, planning and clinical management, includes both planning for needed medications as well as for provision of clinical support to the bedside nurse following WMV. These results suggest that implementation of best practices for WMV may be achieved by interventions focusing on ICU team and family dynamics.

Elements in the communication domain have the ability to result in a WMV process that reduces distress for the patient, family, and staff during death in the ICU. This domain, which functions best when nimble and responsive to changes, is less amenable to strict protocolization in the traditional sense: a checklist cannot, and should not, be seen as a sufficient. A clearly articulated list of stakeholders to engage in the process could serve as a guide or standard for busy ICU teams, but the work of this domain must be adapted to the dynamic particulars of each individual patient-family-care team triad.

The planning domain must address nursing-specific needs from medications to specific actions, and it should anticipate less common scenarios that may arise; a plan for the physician, pharmacy, and RT to be physically available at the bedside for the nurse after WMV is deemed critical. This domain, as constructed by the responses of those interviewed, is more amenable to standard protocolization efforts such as checklists.

The interdisciplinary nature of this study highlighted the need for clear communication among all members of the team, as well as inclusion of all disciplines of the interprofessional team in planning, extubation, and post-extubation management. The desire for greater protocolization, especially among senior team members and senior nurses, speaks to the challenges posed by the wide range of medication dosing that can be given at the end of life (and the fear of "euthanizing" patients), as well as the inexperience of young physicians in training with end-of-life needs and the pace of patient death following WMV.

These findings extend previous research showing that a high-functioning, supportive, integrated ICU team, difficult though it may be to achieve, is an integral part of the perception of good WMV events.<sup>25</sup> Interventions targeting ICU teams to improve patient-/family-centered care have yielded mixed results.<sup>26,27</sup> There is a great need for more in-depth understanding of what it looks like to provide team member support, particularly for bedside nurses. Although investigators have established some avenues for facilitating

effective communication with patients and families,<sup>28–30</sup> the relatively narrow scope and high stakes of WMV at end of life can inform future qualitative work. Specifically, the identification of communication processes that empower bedside nurses to rapidly respond and effectively manage distress at end of life can lead to strategies to enhance these outcomes. Prior work identified a good ethical climate within an ICU as fostering effective communication, with a wide variety of benefits to caregivers and families.<sup>30</sup> The iterative nature of good communication expressed by care team members takes time and resources. Role-specific (eg, nursing) models do exist, and a randomized controlled trial of interdisciplinary support for surrogate decision-makers improved perceptions of communication and family centeredness in end-of-life care.<sup>31,32</sup> Individual patient variation remains a challenge, however, to establishing efficacy in randomized trials of interventions at end of life, and the best process for implementation and dissemination of policies that aid discussions inclusive of family and care among interdisciplinary ICU teams is still unclear.

This study has several limitations. First, ICU clinician interviews were guided by a survey instrument administered with reference to individual patients undergoing WMV. The range of responses offered by participants could be subject to recall bias of the most recent WMV event, rather than broader views of the WMV process itself. This bias was mitigated by survey prompts directing respondents to offer their broader views, as well as guidance from the in-person interviewer. Second, clinicians were enrolled from two medical centers in Boston, Massachusetts. The lack of geographic variation among clinician perspectives of WMV may limit potential generalizability of these findings. Third, because some clinicians were interviewed more than once, there may have been bias in the data due to overweighting those responses and to response fatigue among repeat participants. This represented a small subset (16%) of the 312 responses. The large number of ICU clinicians interviewed, and the diverse group of general and specialized ICUs across two major medical centers, however, bolster the generalizability of our findings across a broad array of ICU settings.

## Conclusions

These study findings suggest the need for more integrated, supportive teams and enhanced communication strategies within teams and between teams and families, as well as improved implementation of established palliative care principles to optimize comfort for patients, families, and staff when pursuing WMV. Core principles of WMV at end of life, and the ability to reduce rates of distress using a protocolized extubation process will facilitate development of best practices for palliative extubation. The fundamental component necessary for a compassionate terminal extubation, however, is less about the actual removal of the endotracheal tube, or even the symptom management immediately following extubation, but rather is dependent upon the team and family dynamics leading up to WMV at end of life.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## ABBREVIATIONS:

<b>MD</b>	Doctor of Medicine
<b>OBSERVE-WMV</b>	Observational Study of the Withdrawal of Mechanical Ventilation
<b>RN</b>	registered nurse
<b>RT</b>	respiratory therapist
<b>WMV</b>	withdrawal of mechanical ventilation

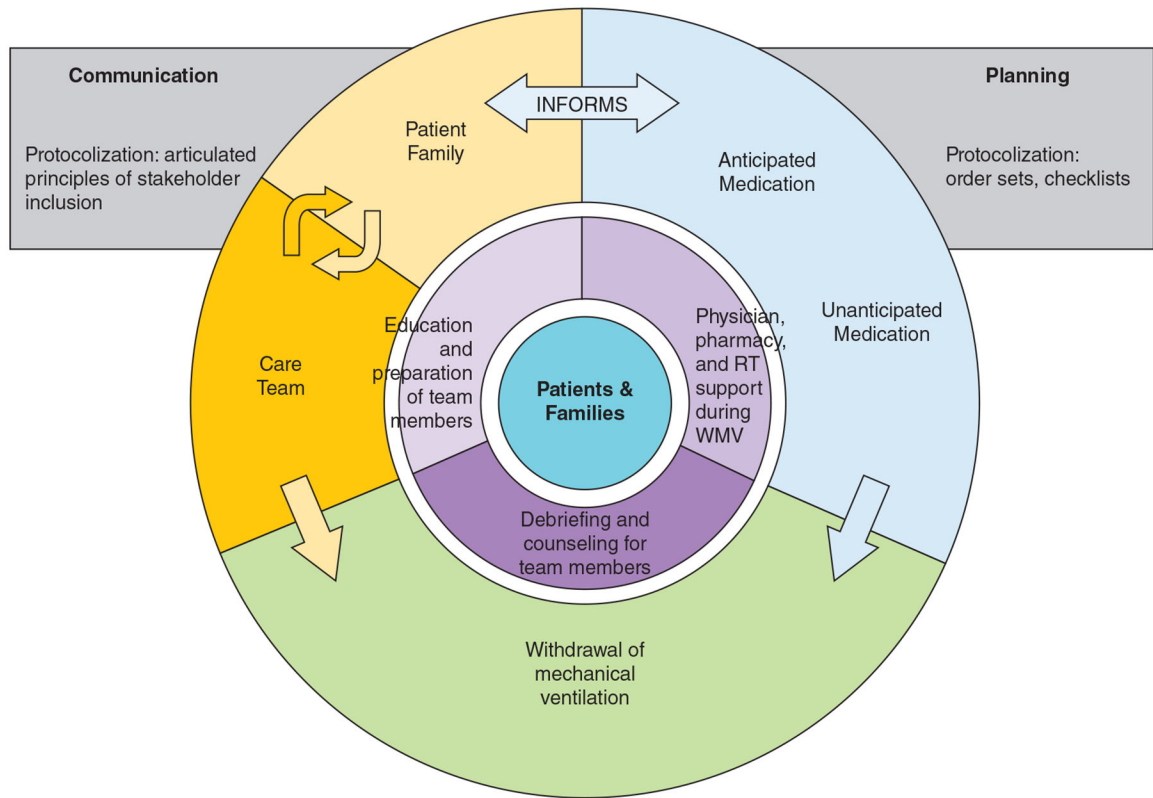
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**Figure 1 –** Schematic framework for tools facilitating appropriate process of WMV in the ICU. RT = respiratory therapist; WMV = withdrawal of mechanical ventilation.

TABLE 1 ]

## Participant Demographic Characteristics

Characteristic	Value
No. of patients	152
Sex	
Female	62 (39)
Male	98 (61)
Age, y	
Mean	70.5
Range	30–94
Length of stay, d	
Mean	8
Range	0–50
ICU type	
Neurological ICU	55 (34)
Medical ICU	41 (26)
Trauma/burn ICU	29 (18)
Cardiac/cardiovascular ICU	21 (13)
Surgical ICU	14 (9)
Interviews	
Total eligible clinicians	456
Total completed	312/456 (68)
In-person	215/312 (69)
Via REDCap	97/312 (31)
Nonresponders	144/456 (32)
Clinicians completing interviews (n = 312) <sup>a</sup>	
RN	140 (44)
RRT	66 (21)
MD	100 (31)
NP	11 (3)
PA	3 (1)
Clinician age, y	38 ± 11
Clinician race	
Asian	37 (12)
Black/more than one race <sup>b</sup>	10 (3)
White	249 (80)
Unknown	16 (5)
Clinician ethnicity	
Hispanic or Latino	13 (4)
Not Hispanic or Latino	290 (93)
Prefer not to answer or unknown	9 (3)
Clinician sex	

Characteristic	Value
Female	225 (72)
Male	87 (28)
Clinician clinical experience, y	10 ± 9.2
Clinician critical care experience, y	8 ± 9.8

Data are presented as No. (%), no./No. (%), or mean ± SD unless otherwise noted. Respiratory therapists (n = 33) were the most common clinician category for repeat interviews, followed by registered nurses (n = 15), and nurse practitioners (n = 2). MD = doctor of medicine; NP = nurse practitioner; PA = physician assistant; RN = registered nurse; RRT = registered respiratory therapist.

<sup>a</sup>Among 312 interviews completed by clinicians, there were 50 (16%) repeat participants.

<sup>b</sup>Categories merged to protect participant identity.

**TABLE 2 ]**  
**Key Communication Elements and Participants Identified for Improving WMV Process**

Communication Element	Participants							
	Patient	RN	MD/APP	RT	Rx	Family	SC	SW
Clear decision to transition to comfort measures	X	X	X			X		
Set exact time for WMV and clearly define plan	X	X	X	X		X	X	X
Designate clinicians to be at bedside and those available if needed		X	X	X				
Plan for patient response		X	X	X			X	X
Plan for presence of family		X	X	X		X	X	X
Family preparation and family response		X	X	X			X	X
Team member support		X	X	X			X	X
Management plan for anticipated symptoms		X	X	X	X			
Early bedside preparation for and control of symptoms		X	X		X			
All medications to ensure patient comfort immediately available (at bedside)		X	X		X			
Timely ordering and delivery of unanticipated medications		X	X		X			

APP = advance practice provider; MD = doctor of medicine; RN = registered nurse; RT = respiratory therapist; Rx = pharmacist; SC = spiritual care; SW = social work; WMV = withdrawal of mechanical ventilation.

TABLE 3 ]

Representative Quotations

Domain	Theme	Subtheme	Representative Quotation
Communication	Team plan	All team members agree upon plan	"I think having a clear concise plan outlined with the care team prior to implementing measures is most important, while maintaining an open mindset after withdrawing ventilation and addressing patient's comfort needs one by one." [RN; 4 years/ critical care experience]
		Decision to transition to comfort care	"Having a team huddle prior to withdrawal of mechanical ventilation is effective in getting everyone involved on the same page with a direct protocol in place including what to say to the family and preference of medication." [no degree or years of experience provided]
		Timing of WMV	"We were all anticipating it since the day prior so patient was generally comfortable both prior to and after the decision was made." [MD/DO; 2 months in critical care]
Family and patient	Family well prepared for the clinical state of their loved one	Consulting teams able to negatively affect the process	"Establish a plan ahead of time and include a protocol for the pathway to extubation that includes: med order set, timing of intervals for vent and/or med weaning, as well as overall timing for the extubation process that includes [input from] social work, clergy, RT, RN, MD, family, etc." [RN; 3.75 years in critical care]
		Family well prepared for the clinical state of their loved one	"I am very angry with our... service. The patient had an AICD as well as a pacer; we asked to have both turned off. They came and turned off the AICD but did not turn off the pacer. We called them multiple times and they refused. This [ie, appearance of cardiac electrical activity after circulatory arrest] was distressing to everyone." [MD/DO; 18 years in critical care]
		Family well prepared for the clinical state of their loved one	"It's important to have family close by in order to maximize time with family member." [no degree or experience information provided]
Iterative relationship	Open, clear communication	Family preferences and beliefs clearly understood and respected	"I always think that family should be present. I realize it's their decision, but it's sad when no one other than the RN and RT is there." [RRT; 38 years' critical care]
		Coordination for family to be present for WMV successful	"Family teaching that the distress patient may exhibit is not uncomfortable to the patient but more difficult for family to watch." [RN; 27 years' critical care experience]
		Clear goals of care conversations	"Can be very difficult for families to see their loved ones in any distress, even if just for a few moments while we are getting meds to give. More education to families prior to extubation. I think sometimes they hear us say removing the tube will make them comfortable but there isn't the realistic expectation that there may be some symptoms that will arise that can be quickly treated." [RN; 11 years' critical care experience]
Iterative relationship	Clear goals of care conversations	Family preferences and beliefs clearly understood and respected	"Informing family of [the] procedure and setting expectations in advance; asking for input from family, patient (if appropriate), and other staff as to what they believe would be the ideal circumstance and what would the [patient] want." [NP; 22 years' critical care experience]
		Coordination for family to be present for WMV successful	"Gut feeling—having family around is very important. No one should die alone." [RRT; 30+ years' critical care experience]
		Clear goals of care conversations	"In my experience I feel that having end-of-life discussions with the patient and their loved ones early on in their stay is crucial in keeping the patients comfortable at the end of their lives because we would then know what he/she would want or not want done at the end of their life." [MSN; 2 years' critical care experience]
Iterative relationship	Clear goals of care conversations	Family preferences and beliefs clearly understood and respected	"Establishing [goals of care] early so that we don't get into a gray area where patient is dying but not technically CMO yet and RN is unable to medicate patient for comfort." [RN; 5 years' critical care experience]
		Coordination for family to be present for WMV successful	"Managing goals of care with social work from the beginning of admission. Allowing the patient's family to have a clear-cut understanding about the patient's status. Overall, proper communication between all involved in the patients care." [RT; 2.5 years' critical care experience]
		Clear goals of care conversations	

Domain	Theme	Subtheme	Representative Quotation
Preparation	Anticipating symptom management needs	Iterative, dynamic, mutually informative	<p>“What would have improved the planning process for WMV would be if we had a huddle with the RN, social worker, RRT, and MD about what we will offer in terms of symptom control and timing of the extubation prior to discussing and planning the timing with the family.” [RN; 2 years in critical care]</p> <p>“Consistent team huddles with all members of the interdisciplinary team might greatly improve this process. These huddles should happen prior to approaching the family to discuss WMV as well as immediately prior to extubation. Having palliative care more involved in the meetings discussing WMV at end of life and then having [a] palliative check-in the day of the planned WMV would help.” [RN; 2 years’ critical care experience]</p> <p>“Have all medications ready and prepped before starting the end-of-life process to optimize the patient’s comfort.” [no degree or experience information provided]</p>
	During team plan	During team plan	<p>“Assuring all members of the team are involved and on the same page; for example, pharmacy with correct medications, doctors with correct orders.” [RT; 5 years’ critical care experience]</p> <p>“Always have a good plan (including meds and correct orders) that you have discussed with the interdisciplinary team and verify that everything is in place and ready to go prior to extubation. Always oral/ET suction first. Always have medications on hand and ready to give (for pain/anxiety/secretions, etc.) Always have a few sets of hands to optimize positioning or so that someone’s able to leave the room to get anything you might need.” [RN; 0.25 year critical care experience]</p>
	Informal, personal rules for what is needed above and beyond team plan	Informal, personal rules for what is needed above and beyond team plan	<p>“More sedation.” [RT; 13 years’ critical care experience]</p>
	Early symptom management essential for successful process	Early symptom management essential for successful process	<p>“Always premedicate the patient even if they look comfortable prior to extubation.” [no degree or experience information provided]</p> <p>“Premedicate in anticipation of respiratory distress and increased work of breathing. Don’t wait until it already happens to try and catch up on it.” [no degree or experience information provided]</p>
	Need to avoid delays in medication delivery	Need to avoid delays in medication delivery	<p>“Having all medications available and ready to use in the room (analgesia, anti-anxiety, secretion management). Having a medication drip already in the room is helpful, you don’t want to have to wait for pharmacy to send this if the patient is uncomfortable post-extubation.” [RN; 2 years’ critical care experience]</p> <p>“Having medications more readily available. Having to wait for a [medication drip] from pharmacy means running in and out of the room to get push doses and the patient spends more time in discomfort. Also, the nurse should pull each medication out of the [medication dispensing cabinet/system] before extubation. Even if they aren’t used they can always be put back, but it is better to be prepared in the room in the moment because it is difficult to tell how a patient will look once the tube is out.” [RN; 2.5 years’ critical care experience]</p>
	Plan for how to get unanticipated medications following WMV	Plan for how to get unanticipated medications following WMV	<p>“Have the order sets in the computer pre-withdrawal of care or somehow initiate once CMO decision made. Pharmacy verification of medications can cause delay in patient comfort. Palliative care order set [is] very helpful including all [drips] and PRN medications available for patient when needed instead of chasing down order and patient having to wait.” [RN; 7 years’ critical care experience]</p> <p>“Readiness and availability of team members such as respiratory therapist and intern MD to move forward with weaning process and adjustment of analgesic medications. Team members were unable to promptly respond to ICU RNs’ pages/calls due to responsibilities with other patients at this time. If communication had been more prompt, the process would have been more streamlined.” [RN; 4 years’ critical care experience]</p>
Team member support	Prior to WMV	Prior to WMV	<p>“It all boils down to communication and preparation. No nurse should be left unsupported or not equipped [with] exactly what’s needed to keep the patient comfortable, and I would like to be sure that NEVER happens. Communicate, plan together, then see it through before extubation begins.” [MD/DO; 18 years’ critical care experience]</p> <p>“Educating people on dignified death in the ICU is so important. The decision to terminally extubate is the last FINITE decision these families make, and sometimes the one that receives the least care team approach. Novice ICU nurses deserve orientation through all stages of ICU level care, end of life is a particularly common piece of that yet gets very little attention from a support perspective. End</p>



Domain	Theme	Subtheme	Representative Quotation
<p><i>Protocolization</i></p>	<p>During WMV process</p>		<p>of life deserves as much finesse as saving a life. If we mentored young nurses or new ICU nurses and MDs through this, I believe it would make a dramatic difference for all involved. Families, patients, and care teams.” [RN; 9 years’ critical care experience]</p>
	<p>After WMV</p>		<p>“Having more RT support and involvement pre- and post-extubation. RT being able to assist with pulmonary hygiene. I feel comfortable managing pain and sedation; however, seeing a dying patient in respiratory distress is a big challenge for me. I rely on the RT to help determine and implement the best interventions to alleviate any suffering.” [RN; 15 years’ critical care experience]</p>
	<p>Desire for greater protocol</p>		<p>“Debriefing for staff after difficult cases; spiritual/social support for staff and family.” [RN; 15 years’ critical care experience]</p>
			<p>“(1) More specific guidelines for premedication: ie, What are the goals pre-WMV? Is it respiratory rate? ... Degree of wakefulness?, etc. (2) Having more medications on hand for the ‘what ifs.’ I would like to see a ‘Palliative med kit’ that includes whatever meds might be needed so everything is available as needed, it’s easy to keep track of what’s been used, and we can be sure we don’t overmedicate. (3) Having a morphine drip prepared and available prior to WMV would also be helpful.” [RN; 12 years’ critical care experience]</p>
	<p>Desire for less protocol</p>		<p>“More education for nursing and physicians. I was initially so cautious to ensure that I wasn’t euthanizing the patients, and I think new physicians are feeling the same thing. Having a standard set of orders with guidelines that both treat the patient appropriately and protect the caregivers would be very helpful.” [RN; 2.5 years’ critical care experience]</p>
			<p>“Every patient is different. There’s no actual way of knowing what could be better for the patient after withdrawal of mechanical ventilation. I feel like keeping them comfortable and making sure they’re not in distress is what we already do.” [no degree or experience information provided]</p>

AICD = automatic implantable cardioverter defibrillator; CMO = comfort measures only; DO = doctor of osteopathic medicine; ET = endotracheal; MD = Doctor of Medicine; MSN = Master of Science in Nursing; NP = nurse practitioner; PRN = pro re nata; RN = registered nurse; RRT = registered respiratory therapist; RT = respiratory therapist; WMV = withdrawal of mechanical ventilation.