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DOCUMENTS

Symptom Assessment for Mechanically Ventilated Patients: Principles and Priorities

An Official American Thoracic Society Workshop Report

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Abstract

Mechanically ventilated patients experience many adverse symptoms, such as anxiety, thirst, and dyspnea. However, these common symptoms are not included in practice guideline recommendations for routine assessment of mechanically ventilated patients. An American Thoracic Society-sponsored workshop with researchers and clinicians with expertise in critical care and symptom management was convened for a discussion of symptom assessment in mechanically ventilated patients. Members included nurses, physicians, a respiratory therapist, a speech–language pathologist, a critical care pharmacist, and a former intensive care unit patient. This report summarizes existing evidence and consensus among workshop participants regarding *1*) symptoms that should be considered for routine assessment of adult patients receiving mechanical ventilation; *2*) key symptom assessment principles; *3*) strategies that support symptom assessment in nonvocal patients; and *4*) areas for future clinical practice development and research. Systematic patient-centered assessment of multiple symptoms has great potential to minimize patient distress and improve the patient experience. A culture shift is necessary to promote ongoing holistic symptom assessment with valid and reliable instruments. This report represents our workgroup consensus on symptom assessment for mechanically ventilated patients. Future work should address how holistic, patient-centered symptom assessment can be embedded into clinical practice.

Keywords: respiration; artificial; symptom assessment; critical care; critical illness

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Contents

Introduction

Over 1 million patients receive mechanical ventilation (MV) annually in an intensive care unit (ICU) in the United States (1). Patients receiving MV occupy 24–41% of ICU beds in the United States and Canada at any time (2, 3). Critically ill mechanically ventilated patients commonly experience major physical and psychological stressors and symptoms, including thirst, inability to communicate, discomfort, pain, fatigue, dyspnea, fear, and loss of control (4–8). Over half of critically ill patients report moderate-to-severe anxiety (8, 9), and more than one-third report feeling afraid despite receiving pharmacological therapies (9–10). The impact of psychological distress experienced by these patients extends far beyond the period of acute critical illness into the recovery phase. Long-term psychological problems after ICU discharge and during recovery include symptoms of posttraumatic stress disorder, anxiety, depression, and reduced overall perceived quality of life (11–15).

ICU evidence-based guidelines recommend minimizing sedation for patients receiving MV and an analgesia-first, symptom-based approach (16, 17). As adoption of these recommendations increases, mechanically ventilated patients will more frequently be alert and interactive, with awareness of their surroundings and the ability to report their symptoms. However, clinical assessment of symptoms other than pain, agitation, and the presence or absence of delirium is not included in the recommendations for routine assessment of mechanically ventilated patients. In addition, sole reliance on patients' self-reporting of symptoms without prompts from healthcare providers may result in inaccurate or missed symptom assessment among this nonvocal patient population and, thereby, missed opportunities for the management of distressing symptoms. Hence, it is imperative that clinicians incorporate into clinical practice a comprehensive and holistic assessment of patient symptoms that extends beyond the current focus on pain, agitation, and the presence or absence of delirium (16, 17). Focusing on additional symptoms such as dyspnea and anxiety could lead to a more targeted, individualized symptom management that further minimizes sedative and opioid use, consistent with the current guidelines (17). A structured, systematic, routine, and accurate approach to symptom assessment carries the significant potential to improve patients' experiences and outcomes during MV and after critical illness.

Workshop Purpose and Methods

In 2021, we convened an ATS (American Thoracic Society)-sponsored workshop with researchers and clinicians who have expertise in critical care and symptom assessment and management to discuss the following questions pertaining to critically ill patients receiving MV in the ICU:

- What symptoms, in addition to pain, agitation, and delirium, should be routinely assessed?
- What strategies can support symptom assessment?
- What are the research and clinical gaps, challenges, and opportunities for symptom assessment in this clinical context?

Workgroup members were recruited by contacting ATS members who are leaders in the field of critical care with a focus on symptom assessment and management or expertise in mechanical ventilation. If experts were not able to participate, we asked for recommendations for potential members. We focused on ensuring workgroup membership across disciplines and locations. Our interdisciplinary, interprofessional workgroup consisted of 19 members, including nurses, physicians, a respiratory therapist, a speech–language pathologist, a psychologist, and a critical care pharmacist. Workgroup members were from the United States, Canada, Australia, and the Netherlands. To include the ICU patient perspective, we asked a former adult ICU patient to review a draft of the workshop report. This feedback was also integrated into this final report.

The initial work of the group occurred between May and July 2021. Three online meetings (total of 7 h) were held during this time, which included short summary presentations synthesizing current literature and group discussions to determine areas of consensus and disagreement that indicated the need for further research. Meeting transcripts and recordings were made available to workgroup members for validation of accuracy. Writing groups were formed to summarize discussions for each question, with drafts developed in the fall 2021 through winter 2022.

This report summarizes existing evidence and consensus gained through this process regarding *1*) symptoms that should be considered for routine assessment of adult patients receiving MV; *2*) key symptom assessment principles; *3*) strategies that support symptom assessment in nonvocal patients; and *4*) areas for future clinical practice development and research.

Symptom Definition and Underlying Assumptions

Multiple symptom definitions were explored to identify a definition aligned with our workshop focus: symptom assessment of patients receiving MV. Symptom models describe a symptom as an individual multidimensional experience (18–21), and symptoms are influenced by factors related to characteristics of a person's health and illness and their environment. In the Symptom Management Model (20, 21), a symptom reflects changes in the biopsychosocial functioning, sensations, or cognition of an individual and is a personal manifestation of disease, injury, or treatment.

Our workgroup defined a symptom as an individual's dynamic, multidimensional distressing sensory and emotional experience incorporating biological, cognitive, psychological, social, and environmental elements. This definition highlights that the cognitively capable person experiencing a symptom is best situated to describe it through self-report, which is recognized as the gold standard for symptom assessment (18–21).

We identified shared underlying assumptions related to symptom assessment among the MV patient population that framed and grounded our discussions throughout the workgroup meetings. The assumptions included:

1. Assessment of symptoms should be patient-centered and obtained using patient self-report whenever possible.
2. Unless a symptom is assessed as absent, it should be presumed that the patient is experiencing the most common symptoms reported by patients receiving MV.
3. Symptom assessment in patients who are receiving MV should be dynamic and adjusted on the basis of the degree of consciousness, illness severity, underlying conditions, and individual personality or behavioral characteristics or traits.
4. Patient-centered goals of symptom assessment and personalized management aim to alleviate suffering, reduce illness burden, improve patient comfort, and remove barriers that obstruct meaningful activities.

Symptoms That Should Be Routinely Assessed in Mechanically Ventilated Patients

Research with ICU survivors during the past 2 decades has highlighted that patients receiving MV experience distressing symptoms that impact their long-term clinical outcomes (22–25). Assessment and management of symptoms during MV in the ICU have been addressed in the PAIS (Pain, Agitation/sedation, Delirium, Immobility, and Sleep disruption Guidelines in Critical Care) (17). However, these guidelines only address certain key symptoms, specifically pain, agitation, delirium, and sleep disruption. We propose that symptoms included in the routine assessment of MV patients should be expanded to incorporate, at minimum, thirst, dyspnea, anxiety, fatigue, and sadness. Among these, thirst appears to be the most intense symptom, and dyspnea is the most distressing symptom for patients receiving MV (8, 9). These symptoms are multifactorial in causation, often occur together, and should be considered multidisciplinary targets for assessment and intervention. Thus, assessment of these symptoms should occur routinely for all MV patients, including those who are sedated, delirious, or not alert.

The list of symptoms experienced by MV patients is extensive; thus, the workgroup proposed that clinicians focus on symptoms that are: *1*) commonly experienced; *2*) bothersome to patients; *3*) potentially disruptive of patient engagement in ICU care and their recovery; *4*) validated, low-burden assessment measures; and *5*) potential targets for effective management interventions. Here, we highlight the application of these criteria to two symptoms. However, this does not preclude the need to consider routine assessment of other common symptoms nor imply that other symptoms, such as thirst or fatigue, do not meet these criteria.

1. Dyspnea is one of the most commonly reported and distressing symptoms in patients receiving MV (26, 27). Dyspnea can also drive other distressing symptoms, such as anxiety, fatigue, and sleep disturbance. Dyspnea can be measured with a validated visual analog scale in most patients (28). Clinicians can intervene in several ways, including adjustment of ventilator settings, managing patient–ventilator asynchrony (29), nonpharmacological strategies such as distraction (30, 31), or pharmacological management (i.e., opioids for patients approaching the end of life) (32).
2. Anxiety is another common symptom (33–35) that can be routinely assessed by members of a multidisciplinary team using a validated instrument (36). Some potentially effective nonpharmacological management strategies include patient-directed music (37, 38), early psychological interventions targeting self-management (39), and visits with family members (40). Given that symptoms overlap, treating one symptom may reduce others. For example, anxiety often overlaps with other symptoms such as dyspnea and fatigue; therefore, management of anxiety may reduce these other symptoms.

Each patient's symptom experience varies, so efforts to identify each patient's common symptoms and then routinely assess those symptoms are essential to ensure patient-centered symptom management.

Symptom Assessment Principles and Strategies

It is imperative that clinicians attempt to assess symptoms among all critically ill patients, including mechanically ventilated nonvocal patients. Presented here are the underlying principles of symptom assessment in MV patients, followed by strategies and tools to inform clinicians' assessment of symptoms. Instruments for assessment of common symptoms such as anxiety (36, 41), dyspnea (28, 42), fatigue (43), and thirst (44) are described elsewhere. Our workgroup discussions were focused on proposed common principles for symptom assessment in patients receiving MV.

Principles of Symptom Assessment

Adhering to existing symptom models, the workgroup suggested some key principles of symptom assessment in MV patients with the goal of decreasing the burden and stress of critical illness and associated treatment and reducing barriers to delivering meaningful therapeutic activities.

What is symptom assessment? Symptom assessment should be:

- Comprehensive and multidimensional, including presence, severity/intensity, associated distress or bothersomeness, disruption in function (e.g., a barrier to ICU activities such as engaging with family or providers or participating in care), and exacerbating and relieving factors;
- Holistic, with a goal of understanding the individual patient symptom experience that includes all aspects of the person (physical, psychological, social, cultural, and spiritual).

When should symptom assessment occur? Symptom assessment should be routine, proactive, and iterative—not just in response to acute patient distress—and integrate routine follow-up after interventions.

Who should be part of symptom assessment?

- The patient's self-report of a symptom should be obtained whenever possible as it represents the gold standard assessment method in a patient-centered model of care.
- Symptom assessment should incorporate clinical expertise from all disciplines, including nurses, physicians, advanced practice providers, pharmacists, respiratory therapists, psychologists, physical therapists, occupational therapists, speech–language pathologists, and palliative care providers.
- Symptom assessment should be initiated by clinicians in collaboration with the patient and their family.

How should symptoms be assessed?

- Facilitating mechanically ventilated patient communication is a key component of symptom assessment. Many patients receiving MV can self-report when provided the opportunity and facilitated by communication aids or strategies adapted to the individual patient.
- When self-report is not possible, alternative assessment methods should be used, including:
    - The observation of symptom-related behaviors and signs by clinicians;
    - Proxy or family (when appropriate) assessment on the basis of behaviors and knowledge of the patient with clear processes for family members to report their perception of patient symptoms to providers;
    - Whenever possible, behavioral or proxy assessment for the presence of any symptom should be confirmed by the patient.
- Structured, whereby symptoms are screened for and assessed with consistent measures using valid instruments when available.
- Symptom assessments should be documented clearly and regularly in the patient's health record.

Basic Communication Strategies and Resources to Support Symptom Assessment

Successful communication with patients receiving MV relies on a patient-focused approach and supports both comprehension and expression. Communication incorporates two main principles: *1*) the ability to understand a message (i.e., comprehension); and *2*) the ability to offer novel (patient-determined) thoughts or respond to incoming messages (i.e., expression). For both comprehension and expression, establishing an environment for communication partners (e.g., clinician and patient) to maximize patient success is vital. This includes eliminating or reducing interference and distractions (e.g., reducing room noise by silencing alarms or radio/television) and ensuring the patient's need for aides (e.g., glasses or hearing aids) is met to provide the opportunity for the patient to clearly hear and focus on the spoken message or visualize a written message (45, 46).

Validating patient comprehension and supporting patient expression requires the identification of accurate and reliable modes of communication (47–49) that are appropriate for the individual patient (50). Some staff may find it challenging to implement communication strategies (51). However, without a reliable communication strategy, input from patients as active participants in their care will be limited. Establishing a mode for verifying comprehension is a necessary first step (52, 53). Assess alertness, including whether the patient is able to open his/her eyes and maintain eye contact to determine the appropriate use of visual communication aids (e.g., pictures and reading). The ability to follow simple commands provides some indication of patient comprehension.

Determining the patient's ability to produce any combination of eye movements, limb gestures, and head movements, or the ability to write, draw, or point will guide the selection of appropriate communication strategies (46, 49, 52, 53). All forms of expression depend on the patient's physical abilities. Forms can range from eye blinks, eye gaze up or down, and finger taps to a patient writing a full-text response. For patients who are more awake, able to pay attention, and physically capable, picture board use, letter board use, use of tablet apps that allow for finger or free drawing, writing on a whiteboard, and using mobile device chat functions may be options. As in assessing understanding, validating the accuracy of expression is an important step, particularly for patients with delirium or variable degrees of alertness. This can include asking patients to communicate (in whatever form) information such as the patient's name, spouse's or caregiver's name, children's names, the city where they live, and age. Importantly, clinicians should validate patient messages by asking, "did I get that right?" or "is that what you meant to say?"

Strategies to assess patient readiness to communicate and adapting communication tools are presented in Table 1. General principles such as reducing the rate of speech, using short, simple sentences, repeating main points, and allowing sufficient time for patient responses support communication with critically ill mechanically ventilated patients. Additional augmentative and alternative communication strategies are highlighted in Table 2. For tracheostomy patients, techniques to support patient vocalization should be explored (45). Finally, consultation with a speech–language pathologist to support patient communication strategies is an important resource when communication with a patient is challenging.

Gaps, Challenges, and Opportunities

Gap in Holistic Understanding of Symptom Experience during MV

The workgroup identified a need for a comprehensive, systematic review focused on symptom prevalence and co-occurring symptoms experienced by adult patients

Table 1. Tips for assessing readiness to communicate and adapting communication tools

Asess patient readiness to communicate (note: these do not preclude the patient's ability to communicate but rather guide communication strategy choices).
- Visual and hearing acuity (ensure the use of hearing aids and glasses)
- Level of alertness
- Presence of delirium or cognitive impairment
- Evaluate patient comprehension (ability to follow simple commands or respond to yes/no questions)

Adapting communication tools (e.g., visual analog or numeric rating scales)
- In general, large, sans serif (i.e., Arial, Helvetica, Tahoma, Calibri), bolded fonts work best.
- Type should be high contrast (i.e., black and white). Colors may be used, but make sure they are iconic to the context (i.e., green = good/go; red = bad/stop).
- Visual simplification (i.e., less is more) will promote more accurate responses because of fewer distractions or fewer stimuli to understand.
- When possible, print on cardstock and/or laminate the materials for repeated use after cleaning the materials. Present materials in front of the patient, keeping in mind that you, as the assessor, need to know/understand the response.

Resources communication with mechanically ventilated patients
- SPEACS-2 communication training and toolkit program: https://go.osu.edu/speacs2
- Patient–provider communication network: https://www.patientprovidercommunication.org

Definition of abbreviation: SPEACS-2 = Study of Patient-Nurse Effectiveness with Assisted Communication Strategies.

receiving MV. The workgroup has identified five symptoms that we propose to be included in routine patient assessment on the basis of the literature and consensus of the group. However, we recognize that the patient experience encompasses many additional symptoms necessitating a more thorough systematic review to guide holistic symptom assessment. Although acknowledging the methodological challenges and inconsistencies in the current literature, a cohesive review will provide data on the most common symptoms and symptom clusters experienced by MV patients to help clinicians prioritize symptom assessment. Including research on symptom clusters in other acute and chronic conditions (e.g., cancers, heart failure, etc.) may be helpful in illuminating methodological issues as well as co-occurring symptoms. A holistic framework applicable to MV in which the patient is rendered nonvocal and, especially in the acute phase, in which patients often experience varying

Table 2. Communication strategy descriptions

Communication Strategy	Description/Purpose
Establishing a clear yes/no signal (46)	Ensuring there is an established yes/no signal that can be consistently performed by the patient (e.g., nod/shake head; tap finger/foot; eye blinks; eye gaze (up or down). Ensure all providers use the same method for yes/no responses. Post a sign or communication plan with the patient's yes/no method.
Tagged yes/no (46)	The communication partner ends (tags) questions with the phrase "Yes … or no?" and an appropriate signal/gesture (head nod or shake), alerting the patient to the possible response choices.
Writing (whiteboard or pen/paper)	Writing utensil should be large enough for the patient to hold comfortably. Consult OT for an orthotic pen holder if needed. Use clipboards and spiral notebooks so patients can refer to previous messages.
Written choice (63)	The CP asks questions and provides the patient with keywords for possible answers in large print on paper; CP asks the questions, followed by reading answers out loud while pointing to choices, then instructs the patient to point to their selection/response.
Gesture/signal dictionary (63)	Posting of signals/gestures commonly used by the patient and their meanings so patient and CP can refer to them (e.g., gestures for particular symptoms, encourage pointing to body part).
First-letter spelling with mouthed speech (46)	Patients point to the first letter on the alphabet board and then mouth the word.
Alphabet boards (46)	The spelling of messages by pointing to letters printed on the board.
Picture board	Provision of a board with pictures depicting common patient needs, symptoms, questions, or responses.
iPad or tablet applications	Allow text or picture-to-voice communication. The patient may need to use a stylus.

Definition of abbreviations: CP = communication partner; OT = occupational therapy.

degrees of sedation and/or consciousness, is needed to guide this review and future research on symptoms. Furthermore, this review should identify our current understanding of the symptom experience for subpopulations in the critical care unit, including patients with delirium, patients at the end of life, and across the lifespan (pediatric to older adult).

Gap in Symptom Assessment Tools

Current approaches to symptom assessment among mechanically ventilated patients are limited to a few symptoms but fail to capture the entire spectrum of symptoms experienced by patients. Much of symptom assessment research among mechanically ventilated patients has used tools validated in other populations (9, 54). Because mechanically ventilated patients are often impaired or unable (e.g., comatose) to report symptoms, alternative measures of symptom assessment (e.g., observational) are a necessary yet underdeveloped area of research. There is a need for greater development and testing of measurement tools that are psychometrically sound, efficient, and pragmatic for MV patient populations capturing the full spectrum of symptoms patients are potentially experiencing. In practice, this translates to a gap in the documentation of symptoms and communication among team members, particularly at times such as shift changes or during handoffs. A feasible yet efficient system that incorporates standard symptom language and broad symptom assessment is needed.

Gap in Alternative Communication Tools

Inadequate and inconsistent communication strategies employed by critical care clinicians to facilitate communication with MV patients create barriers to understanding and accurately assessing the patient's symptom experience. This gap can be addressed by routine speech–language pathologist consultation (55), implementation of communication training and competency testing for all members of the critical care team (56, 57), and by incorporating augmentative and alternative communication tools as standard practice with mechanically ventilated patients (49, 58, 59). Evidence-based approaches to minimizing sedation use are necessary to optimize mechanically ventilated patients' communication opportunities and abilities. Finally, family engagement in bedside communication, including the use of augmentative and alternative communication tools and strategies, can improve symptom recognition and assessment (60, 61).

Gap in Pediatric Symptom Assessment during MV

Our workgroup was primarily focused on adult patients receiving MV throughout our sessions. We suggest that similar work be undertaken with the pediatric critically ill patient population. Although much of the information incorporated in this report is relevant to the pediatric population, there may be unique symptoms or symptom clusters that should be systematically evaluated from a developmental and family perspective.

Challenge and Opportunity: Culture Shift to Prioritize Symptom Assessment

Recognition of the importance of symptom assessment and the MV patients' symptom experience requires a culture shift. To support holistic symptom assessment and management, systems or workflow issues that artificially divide and separate interdisciplinary team members' efforts and roles must be addressed. The nurse should not solely assume primary responsibility for symptom assessment and documentation. A shared interdisciplinary approach is needed to improve symptom assessment, create or adopt universal measurement tools, define common language and documentation of symptom assessment, and develop a process for comprehensive symptom assessment and management during interdisciplinary team rounds and patient handoffs. Research approaches in this area should include both implementation science (e.g., sedation management and communication facilitation) as well as participatory action research and experience-based codesign research (62).

Implementation science can help translate holistic symptom assessment into routine care and measure the impact of new procedures and processes related to symptom assessment and management. Participatory action research and experience-based codesign methods can be used to promote a culture shift that prioritizes collaborative, interdisciplinary symptom assessment and management—to be successful, stakeholders should include former MV patients, family caregivers, the interprofessional team, and hospital leaders. Interprofessional skill building in symptom assessment should include the use of simulation exercises with multidisciplinary team members to conduct collaborative, consistent, and valid symptom assessments. Finally, research that connects symptom assessment and management with MV patient outcomes and long-term recovery is needed.

Conclusions

Holistic symptom assessment represents an opportunity for clinicians to demonstrate compassion and provide support to patients receiving MV. Systematic patient-centered assessment of symptoms is the first step toward minimizing patient distress and improving the patient experience. This is the shared responsibility of all caregivers. A culture shift is necessary to promote ongoing symptom assessments with valid and reliable instruments. Although this report represents our workgroup consensus on symptom assessment principles and priorities for MV patients, more work is needed to understand how holistic, patient-centered symptom assessment can be embedded into clinical practice. Without a thorough assessment of all symptoms that patients experience during MV, we cannot provide compassionate and comprehensive care for this population. ■

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